DOCTOR OF PHILOSOPHY

Experiences of the Older Person with Cancer
A qualitative study of medical and specialist ward settings

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Finally, this thesis is dedicated in memory of my mother, Lydia and my father, Ernest, who always made everything and anything seem possible and understood that through education comes empowerment.

Declaration

I, Antonia Lydia Lannie, declare that I am the author of the thesis. Unless otherwise stated, I have consulted all the references cited. I have carried out the work of which the thesis is a record and the work has not been previously accepted for any higher degree.

Antonia Lydia Lannie.....

Date.....

Summary

This thesis combines two research strands: cancer patients' experiences and care of the older person. Previous cancer research has identified that health care professionals may treat older people with cancer differently, perceiving them as having less power; offering fewer treatment options; and less access to specialist cancer care. This qualitative study seeks to illuminate and compare the experiences of patients and health care professionals in two contrasting hospital wards (specialist and medical).

This study considers how cancer patients manage their psychological and social needs. It also explores the challenges for health care professionals. Purposive sampling captures diversity of patient and health care professionals' perceptions. Semi-structured interviews were conducted with patients and focus groups and semi-structured interviews with professionals. Analysis highlighted commonalities and also different emphasis accorded to issues such as societal perceptions, expectations of care, life stage, relationships, identity, and emotions.

The hospital serves as a 'halfway house' for patients, allowing them to work through challenges in a 'protected' environment. However, health care professionals had difficulties addressing the future and managing some therapeutic opportunities. These are discussed using the thematic codes of 'professional etiquette', and types of emotional engagement with patients. Although older people with cancer are often perceived as a homogenous group they may have varying psychosocial needs. Moreover, patients' understanding is frequently more sophisticated than professionals acknowledge.

Finally the thesis will discuss the implications of this research for professional education, assessment and provision of care for the older person with cancer.

CHAPTER ONE

Setting the Scene

The aim of this chapter is to give an overview of the thesis content and what contribution is to be achieved. This chapter will give a broad introduction to the intent of the thesis, including a reflective account of my personal reasons for undertaking the study. A rationale, identifying key studies, will then underpin the aim of the thesis. The structure of the thesis will then be outlined.

Introduction

This study came about as a result of my concern for the care of older people with cancer during my career as a charge nurse, senior nurse manager and lecturer in a variety of clinical settings (cancer centre[1], cancer unit[2] and community) and a Lecturer for Marie Curie Cancer Care, Macmillan Cancer Relief and the University of Dundee. While serving as a Macmillan educator in the late 1990s, I realized that care delivery in cancer and palliative care for older patients was lacking, whether in a hospital or care home setting. Due to the lack of specialist cancer and geriatric services, care delivery was left to registered nurses who were not knowledgeable or skilled in caring for older people with

[1] Regional Cancer Centres (RCCs) are cancer care hospitals and research institutes. The name 'Regional' relates to institutions which cater to a designated region, usually a number of districts in the country.

[2] A cancer unit is either a single hospital or two or more hospitals. A cancer unit is defined as a health authority and/or trust(s) capable of managing patients with a defined range of cancers to contemporary standards of good practice or of so doing within a finite development period (Department of Health, 2004).

cancer. Throughout the cancer journey, deficiencies in professionals' education and experience were often resulting in inadequate management of the patients' illness from an emotional and clinical perspective.

Rationale for the study

Cancer is a chronic illness within an ageing population (Department of Health, 2004; Information Services Division Scotland, 2013). The European Community (EC) states that one million cases of cancer are diagnosed per year and that 55% of these cancers occur in the over-65 age range (Boyle and Smans, 2008). The incidence of cancer increases rapidly with age and is 12 to 36 times higher in individuals aged 65 years old than in individuals aged 25 to 44 years, and 2 to 3 times more common than in persons aged 45 to 64 years old (Avis and Deimling, 2008; NHS Scotland 2004a, 2004b, 2005; Repetto et al., 2003; Vercelli et al., 2000; Yancik, 2005; Yancik and Ries, 2004). Specifically, 70% of deaths attributed to all cancers are in men and women 75 years and older. In Scotland, it is estimated that 1 in 3 people will develop some form of cancer during their lifetime, and that around 1 in 9 males and 1 in 7 females will develop some form of cancer before the age of 65. Having survived to the age of 65 without cancer, the risk of getting cancer subsequently is 1 in 3 for males and 1 in 4 for females (Scottish Government, 2008a). Thus, cancer incidence in the older person is of significant demographic importance.

The majority of people over 65 years old who have cancer are cared for in general hospitals, which are commonly not categorized as 'cancer centres' but as 'cancer units'. As specific data were reviewed in the health board region in which the study was being carried out, I saw the need to explore how care is provided in various ward settings, as

patients were increasingly being admitted to the general hospital and into wards which did not provide specialized care either for cancer or for the older person.

Research in this area to date has largely been conducted in care homes (Hockley et al., 2004; Hockley et al., 2005; Hockley, 2006), or in a cancer centre (Chouliara et al., 2004b). Having been aware of Hockley's work in care homes (the Bridges Project [3]) and the study carried out by Chouliara et al. (2004b) in a cancer centre, I realized there was a gap in the research and a need to explore care in a general hospital situated between two cancer centres. Chouliara's pilot study suggested that patients cared for on general wards within a hospital which had a cancer centre were not always given specialist cancer care. This gave me the impetus to explore what the experiences of older people were when being cared for in general hospitals which did not have a specialist cancer centre. Exploring care in the two wards developed an understanding of:

> How older people respond to professionals in different ward settings considering their illness and psycho-adaptive coping.
>
> How professionals engage with older people with cancer in different ward settings.

Establishing the social and clinical tensions that arise when caring for older people with cancer provides insight into the attributes of 'person-centred' care[4]. The focus relates

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[3] In 1999, the Board of Governors at St. Columba's Hospice provided funds for a 5-year action research project to bridge the gap between the hospice and local nursing homes (Bridges Initiative, 1999-2004).

[4] The Crossing the Quality Chasm and the Scottish Government Document (2007) have been relabelled as 'person-centred care' in the Scottish Government (2010) health care strategy, but this is still defined primarily in terms of responsiveness to individuals receiving care. It is defined as: 'responsive to individual personal preferences, needs and values, and assuring that patient values guide all clinical decisions' (p. 8).

particularly to the diversity of psychosocial and clinical discourse between patients and professionals.

Aim of the thesis

The overall aim of the study is to generate a fuller understanding of the older person's experience with cancer in two ward settings. The aim will be achieved by focusing on three research questions:

How do these two settings (medical ward and specialist ward) shape:

1) The experiences of the older person with cancer in different ward settings?

2) Professionals' perspectives of the older person with cancer?

3) The factors which influence care in different ward settings?

This thesis departs from previous work in eliciting and comparing multiple accounts, from patients *and* professionals, of care delivery and the psychosocial adaptive concepts and processes involved.

Discipline

It is salient to discuss the main discipline of the thesis as it alludes to the norms and values which gauge professional behaviour. The discipline which underpins this study is nursing. This is for three reasons. Firstly, this is due to the fact that nursing is the primary profession of the researcher and acknowledging the researcher's background is as important as the participants in how data generation is perceived and managed (Allen, 2004; Johnson, 2009). The role of the researcher is not to determine the value or veracity

of different accounts, but to understand *how* 'situated accounts' are told and what they allow speakers to achieve. This gives the researcher an understanding of a particular aspect of their story while placing less importance on other aspects, which is significant in the process of reflexivity (Barbour, 2008). The process of reflexivity is discussed further on pages 112-118.

Secondly, nursing is chosen as the underlying discipline as it has been described as an inherent human process of establishing well-being, manifested by complexity and *integration* in human systems drawing upon social science (Reed, 1997). As a result, the nursing role has been argued as therapeutic in that interventions are more mutually negotiated (Lanceley, 2008; Scottish Government, 2008c). Thirdly, the therapeutic interaction of a person-centred approach is highlighted as significant through the underpinning ontology and epistemology of social construction and social constructionism (see pages 69-70).

Social construction and social constructionism is underpinned by social interaction in society, which has been primarily advocated in sociology. The chosen approach also intertwines with the social concept of old age and the societal labelling of cancer. Whilst it is important to explore the knowledge generated by researchers from multiple disciplines such as health psychology, the central discipline of this study is firmly placed in the applied health research context.

Structure of the thesis

The thesis structure is made up of background and literature review followed by the methodology and two analysis chapters which move from the descriptive to the more

theoretical, relating to the care environment and emotion management. The final chapter discusses the main themes of the thesis.

Chapter 1 gives a summary of the main themes underpinning the thesis and relating to the broad content of each of the chapters.

Chapter 2 provides a broad but selective review of the literature which focuses centrally on the experience of cancer and the older person. Consideration is given to a range of patient and professional perspectives, including diagnosis, age group, place of care, gender, clinical and psychosocial and perspectives. The review is grouped into three core themes. Firstly, *the care environment* considers issues of locality and focus of care[5]: specialist and non-specialist areas. Secondly, literature related to *psychosocial care* will be critically debated, including sections encompassing specialist and non-specialist nurses and education. Thirdly, literature related to biographical characteristics including older people with specific cancers will be discussed. The chapter is organized within the structure of themes and sub-themes to support the data generation and analysis of the research. Gaps are identified from the review which will justify the aim and research questions of this study.

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[5] The focus of care is defined as the primary goal within care delivery. There are four main care categories within cancer and palliative care. Firstly, *acute care* deals with the more severe symptoms and/or personal distress associated with exacerbation of a symptom. Secondly, *supportive care* is an 'umbrella' term for all services, both generalist and specialist, that may be required to support people with life-threatening illnesses. It is not a response to a particular disease or its stage, but is based on an assumption that people have needs for supportive care from the time that the possibility of a life-threatening condition is raised (National Council for Palliative Care, 2007). Thirdly, *palliative care* is the active holistic care of patients with advanced, progressive illness. Fourthly, *end of life care* helps all those with advanced, progressive and/or incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both the patient and the family to be identified and met throughout the last phase of life and into bereavement. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support (National Council for Palliative Care, 2007).

Chapter 3 discusses social construction and social constructionism and why this is the chosen methodology for this study. The chapter suggests that knowledge becomes a reality through language and discourse. Social constructionism assumes an interpretive position which focuses on the relationship between reality and knowledge as interconnected and arbitrary.

Following the research questions, the methodology is further developed to include purposeful sampling, data generation through focus groups, semi-structured interviews and dissemination focus groups. Data are generated through the lenses of *social, clinical, professional, personal, cancer, older, person* and *patient.* Analysis involves a systematic thematic analysis in order to identify the patterning in the data. Ethical issues within the study are also addressed and the importance of reflexivity as a researcher is debated critically.

The next two chapters present the findings of the study. The main aim of these chapters is to present a critical analysis of the data from transcripts and theory. Findings have been organized conceptually to illustrate the process of care delivery within two ward settings and the psychosocial factors and processes which influence the experience of older people and the professionals who care for them.

Chapter 4 will debate the attributes of each of the care environments and the challenges for care delivery when delivering cancer and palliative care in these settings. Patients and professionals engage with older people in different ways, depending on therapeutic opportunities within the ward context. Particular challenges in care delivery relate to

symptom management, decision making and the transition from cure to palliative care[6].

There were intra-professional tensions with regard to appropriate care for older people with cancer, relating to cessation of treatment. Professional roles within the ward setting demonstrated a variety of approaches to patients. Factors which influenced these approaches related to the remit of professional roles. The nursing role was pivotal in the delivery and maintenance of a therapeutic relationship. Barriers to delivering cancer, and gerontology care were related to a lack of education and experience and poor intra-professional collaboration.

Chapter 5 will explore emotion management from patients' and professionals' perspectives. Older people with cancer tend to protect their family about their illness and end of life care. Some patients manage practical arrangements and others deal with family emotions. There are cultural and gender-related characteristics which encompass their beliefs and affect their biographical experience. Older patients used their past lives and comparison to other patients to make sense of their illness. Some patients used their past experiences of hospitals and illness to adapt to being hospitalized. This interpretive approach generates reassurance and a sociable atmosphere with fellow patients.

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[6] Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (WHO, 2011).

The chapter will discuss how cancer is seen as either disruptive to older people or as non-disruptive. Through analysis of past lives and stage of illness of participants, data will highlight how broad cultural and moral discourses and patterns of social interaction combine to 'down-play' participants' emotions.

The chapter also addresses the emotional management difficulties for professionals in not knowing what to say to patients. They found it difficult to balance the professional self with the inner self. This resulted in discourse which was superficial, reflective or authentic in intent. The issues discovered ranged from a lack of emotional involvement through to emotional personification such as 'that could be my mum or dad in that bed'. Professionals looked to their past lives and inner self to enable empathy for patients while addressing the professional 'etiquette' inherent in their role. Nurses were best able to facilitate people's emotions.

Chapter 6 critically discusses two topics: the care environment and emotion management. Current literature is used to demonstrate what is unique about this study and then recommendations for practice are given. Finally, recommendations for future research, practice development, education and policy will be given relating to the two main areas from the study.

Chapter summary

The care of older people with cancer is an increasingly relevant concern. Patients who are over 65 with cancer are not always admitted to an appropriate ward setting that considers their physical and psychosocial needs. There appears to be a gap in the literature and an argument for a study which generates a fuller understanding of the experiences of older

people with cancer in a general hospital setting. This study specifically acknowledges the context in which care takes place; the experiences of older patients with cancer; professionals' emotion management with patients who are older with cancer; and interpersonal dealings between patients and professionals.

The next chapter considers existing evidence in this field and provides a critical background for the development of this study.

CHAPTER TWO

Literature Review

Introduction

This chapter is divided into three broad sections. The first section begins with an overview of the literature search, explaining what type of review was undertaken and why. The second section is divided into themes which were generated from the review. The studies considered relate to various settings, contrasting stages and different cancers. Professionals' perspectives of care delivery relate to various care settings and the differences in experiences of caring for the older person with cancer. The third section of the literature review identifies gaps in the literature and support for this study.

An overview of the literature review

The purpose of the literature review is to:

- Discover the issues relevant to the key topic of the care of the older person with cancer.
- Synthesize the literature to gain a perspective which will inform the epistemology, methodology and data generation methods of the study.
- Identify relationships between theory and gaps in clinical practice.

The questions guiding the literature review are:

- What are the experiences of the older person with cancer in different care settings?
- What are professionals' perspectives of the older person with cancer in different care settings?
- What are the factors which influence care in different care settings?

The type of literature review undertaken is defined as a scoping review (Arksey and O'Malley, 2005). With particular reference to nursing, considering many scoping reviews, Davis et al. (2009) stated they were contextualized by: policy and other organizational documentary analyses; consultancy with stakeholders/key informants; scoping questionnaire surveys; individual semi-structured and case study interviews; and focus groups. The methodological combinations of these inquiries fell within three overarching categories:

(1) Review of theoretical and empirical literature.

(2) Combination of one or more dimensions from category 1, plus other qualitative and/or mixed research elements, including consulting stakeholders/key informants.

(3) Solely empirical research elements presented as scoping.

This scoping review adopted category 2, as there was a need for a review and critique of empirical literature that would include key stakeholders and other theoretical literature. This review also uses data from policy and practice guidelines, to provide contextual

background. Unlike a systematic review, in this review there was no weighting allocated to the accounts, but rather a grouping was made of studies which related to a theme.

The definition of a scoping review (Davis et al., 2009) is:

> A review that demonstrates procedural and methodological rigour in its application. In addition, explicit identification of practical, methodological and theoretical limitations of the approach undertaken should be described to ensure that the usefulness and value of the findings are appropriately interpreted and used by others (p. 182).

A scoping review has already been undertaken in other studies (Hagell and Bourke Dowling, 1999; Griffiths and Norman, 2012; Kelly et al., 2006). Arksey and O'Malley (2005) and Hart (2010) remind us that there is no ideal type of literature review, but rather all review methods offer a set of tools that need to be appropriately used.

Search strategy

This section will outline how the search strategy was developed and carried out. The strategy consisted of using electronic search engines on computer databases, searching reference lists, hand-searching relevant journals and contacting authors directly. The main source of the literature search was online subject-specific electronic databases accessed through Dundee University and the RCN library. In addition, I reviewed existing networks, relevant organizations and conferences from the search period. The search strategies were either electronic or opportunistic. Electronic databases offer three ways to search: broad-based, thesauri and advanced searching. Broad-based reviews returned a high number of false positives in comparison to the other two strategies. Using all three

strategies ensured that all appropriate resources had been utilized. The databases with inclusion dates are outlined in Appendix A.

Search terms

Identifying the keywords was not decided on the initial review, but was seen as an ongoing process while becoming familiar with the databases. Due to searching for studies in different countries, many different words that described the topic were applied, using the thesauri (subject headings). The subject headings differed according to the origins of the databases: for example, I realized that CINAHL had an American bias, while BNI had a British focus.

The search terms were chosen to include the attributes of care delivery within a ward setting. The search terms were; 'older person' or 'elderly' or 'older people', 'cancer' or 'neoplasm*', 'professional perspective*', 'caring', 'ageism', 'non-cancer ward*' or 'general medical ward*', 'cancer ward*' or 'oncology ward*' or 'specialist wards*', 'education' or 'experience*' (the * allows plurals to be included). I also used the $ facility, depending on the database being searched. I also included the search words that were present in the abstract.

Boolean terms

Branley (2004) states that if one searches using single words there may be too many results. A standard technique for combining search terms which helped restrict or expand terms was to use the Boolean terms of 'AND' or 'OR'. Due to the breadth of literature that was being covered, I strategically refined the search terms by the use of 'and' as indicated

by researchers (Seale, 2004; Aveyard, 2010). I also used the multiple character wild card (*), which allows the computer to search all possible characters within words. Search engines further enabled refinement of the wording by adding thesaurus terms in addition to my key words.

Identifying relevant literature

It is recognized that electronic searches are not 100% comprehensive. Some of the literature used may not be categorized using the search terms. Montori et al. (2004) noted that articles were frequently found by chance when they reviewed the literature. Greenhalgh and Peacock (2005) emphasize the importance of using many approaches to identify appropriate literature. Therefore, hand searching journals, searching contents and reference lists was also carried out. Periodically, articles were found while looking at major journal sites or reviewing articles which were recommended by friends or colleagues.

It was also valuable to source systematic reviews and other literature reviews to ensure that articles were also included in the scoping review where applicable. This identified further references, although a saturation point was reached when no others were found (Chouliara et al., 2004c; Hughes et al., 2009; Bellury et al., 2011).

Being asked to review an article for the *European Journal of Oncology Nursing* relating to the older person with cancer helped me to further reflect on the chosen studies. It was also found useful to search references from key authors who were instrumental in developing major theoretical debates, such as Kagan (2008). This gave further insight into other possible studies or explanations which might be of interest in synthesizing the literature.

Inclusion and exclusion criteria

By using inclusion and exclusion criteria it was possible to identify the literature which addresses the research questions (Mason, 2002). Specific wording of the research questions, which articulated the focus of research. The inclusion and exclusion criteria included consideration of population and type of study.

Population

The exclusion criteria were: studies which solely included people without a diagnosis of cancer or who were under the age of 65, which were not written in English and/or were carried out before 1995.

It is important to note that the definition of ‘old’ or ‘elderly’ based on chronological age appears unclear in the research. Studies report varying age ranges. Cohen (2006) uses the age of 75 to define the older person, while Balducci (2000) defines 70 years of age as the lower age of the range for screening of frailty, and Redmond and Aapro (1997, p. 236) define the age of 65 as the lowest range. Studies were included which used the age range of 65 and above, as this is perceived as the starting point for old age in standardized clinical guidelines (Oncology Nursing Society and Geriatric Oncology Consortium, 2007). The World Health Organization states that:

> Most developed world countries have accepted the chronological age of 65 years as a definition of 'elderly' or older person, but like many westernized concepts, this does not adapt well to the situation in Africa. While this definition is somewhat arbitrary, it is many times associated with the age at which one can begin to receive pension benefits. At the moment, there is no United Nations (UN) standard numerical criterion, but the UN agreed cut off is 60+ years to refer to the older population. Although there are commonly used definitions of old age, there is no general agreement on the age at which a person becomes old.

> The common use of a calendar age to mark the threshold of old age assumes equivalence with biological age, yet at the same time, it is generally accepted that these two are not necessarily synonymous (WHO, *Health statistics and health information systems,* 2013).

Type of study

The inclusion criteria were that articles were peer reviewed research studies relating to the older person with cancer and/or care in ward settings, as well as professional and patient perspectives and education relating to care of the older cancer patient. Comparative studies were included which looked at both young and old people, cancer and non-cancer participants and cancer-specific studies. A large date range was used in order to include potential studies which reflected major developments in oncology policy planning in relation to how services were organized in Scotland and England (Calman and Hine, 1995; Department of Health, 2001; Scottish Executive Health Department, 2003a, 2003b; Scottish Government, 2008a, 2008b, 2008c, 2011).

Retrieved and reviewed studies

Aveyard (2010) and Mason (2002) discuss two principles which guide inclusion of studies for a review. These are: is the literature relevant to the review? Is the study within my hierarchy of evidence?[7] Critical appraisal was also important in assessing the relevance of a paper, identifying strengths and limitations. The diversity of mainly qualitative studies made it difficult to find an appraisal tool that was appropriate for every paper. Lincoln and

[7] The hierarchy of evidence is a grading system for assessing the quality of evidence, which is categorized into systematic reviews and meta-analysis, Randomised Controlled Trials, cohort studies, case-controlled studies, surveys, case reports, qualitative studies, expert opinion and anecdotal opinion.

Guba (1985) argue that the terms ‘credibility’ and ‘transferability’ are more suitable for assessing qualitative papers than ‘validity’ and ‘reliability’. It is argued that diversity of qualitative methods makes applying a simple checklist or appraisal tool difficult (Barbour, 2001 and 2008). However, the benefits of using a critical appraisal tool rather than an unstructured approach have been highlighted (Polit and Beck, 2010; Greenhalgh and Taylor, 1997). Retrieved articles were reviewed considering their purpose, aim, focus and process of research (as identified in the review process adapted from Patton, 1990). Please see Table 1 below.

Table 1: The review process in study selection

The review process involved in study selection (adapted from Patton, 1990)
Consider the: • Aim • Theoretical stance • Sampling strategy • Types of data • Management of data • Analytical approach • Strengths and limitations • Gaps in the literature.

Patton’s review process was applied when reviewing all studies. Patton (1990) was recommended by Hart (2010) as a clear summary of the main features of the research design. Patton’s review process facilitated the ‘charting’ of articles.

Charting the literature

An approach which is commonly used in the review process has been defined by several authors (Noblit and Hare, 1988; Paterson et al., 2001) as 'charting' the data. 'Charting', as defined by Arksey and O'Malley (2005), was adapted from Ritchie and Spencer (1994)[8]. It is a technique for synthesizing and interpreting literature according to key themes; the charting process includes information about the study, such as the topic, study design, and outcome measures. Appendix B gives an example of the charting process, using some articles that were charted and showing why studies were coded into themes and why they were chosen. The charting process enabled a systematic review of the studies, developing themes and comparing sub-themes. There was consideration of how the themes linked together, identifying consistent and conflicting themes within each.

In particular, studies such as Hockley et al. (2005) or Chouliara et al. (2004b), whose focus is on the clinical setting, were 'core'[9] to the narrative of this thesis. As articles were compared and contrasted, further scrutiny refined initial findings. The process of reviewing studies was an ongoing iterative process. Morse (1991) stated that this iterative process of comparison is similar to that within qualitative data analysis.

The charting process: a thematic review of literature

When examining the literature, the historical development of the literature emerged. Studies were initially of a clinical nature, focusing on treatments and side-effects and the

[8] Ritchie and Spencer also discuss this approach in qualitative data analysis as a means to compare and contrast studies.

[9] Particular studies which were central to the argument were defined as 'core' papers, to which other literature was compared.

intent of treating older people, with less emphasis on the psychosocial aspects of care. However, the psychosocial aspects were more predominant from 2005 onwards. These aspects of care seemed to be further refined between 2008 and 2012, when there was distinct reference to physical ageing and cancer, and psychosocial adaptations particular to old age. Through charting it was apparent that literature could be categorized from the macro domains of literature (organizational, clinical setting, contextual), to the more micro (professional interactions with patients, gender, types of cancer). In consideration of the macro and micro aspects of the literature, the themes and sub-themes were organized in the following order:

- Firstly, the major theme of the care environment, and the sub-themes; rural or urban locality, specialist and non-specialist care settings.

- Secondly, the major theme of professional perspectives, and the sub-themes; focus of care, interdisciplinary collaboration, specialist and non-specialist roles and education.

- Thirdly, the major theme of young and old, including sub-themes of gender related adaptive issues and older people with specific cancers.

First major theme: the care environment

Studies relating to the care environment give a clear indication that where the older person is cared for is significant to their experience of cancer care delivery. In this study, the ‘care environment’ is described as the location of care, which gives indications of the referral patterns, and qualities of professionals including resources which enable care delivery. To

enable a broader perspective of the care environment, the focus of studies includes the geographical location of care: rural or urban, specialist and non-specialist areas.

Rural or urban

Studies by Pitchforth et al. (2002) and Austin and Russell (2003) demonstrate that older patients who are admitted to hospital in an urban locality have less access to clinical and supportive care. There is less participation in clinical trials in both rural and urban settings (Burdette-Radoux and Muss, 2006; Foster et al., 2010).

Another study signifies differences in stage of illness in colorectal and lung cancer comparing different locations (Campbell et al., 2001). The studies suggest that services rather than age are the issue. However, age, particularly being 65 and over, is seen to be a statistically negative predictor for receiving treatment and having poorer outcomes of care than their younger counterparts (Pitchforth et al., 2002; Austin and Russell, 2003). The aim of Pitchforth et al.'s study (2002) was to explore care for colorectal patients in a non-specialist setting and a cancer centre. Pitchforth et al.'s review of databases demonstrated that only 47 out of 4123 patients aged 75 or older received chemotherapy. This study demonstrates that, when compared to a cancer centre, patients admitted to a non-specialist setting were less likely to receive chemotherapy. The low numbers of patients aged 75 or older who received chemotherapy demonstrates that older age is a statistically significant negative predictor for receiving chemotherapy as well as the place of care. It is unclear whether patients were not given treatment as a result of their chronological or functional age. There is also literature to suggest the type of hospital (whether a major cancer centre or not) influences the care experience.

Bain and Campbell (2000) carried out a qualitative study which aimed at exploring the clinical treatment and experience of 22 older colorectal cancer patients (aged 60-70 plus years) and 10 carers, comparing a non-cancer centre and a cancer centre[10]. The sample consisted of 22 patients, at various stages of their treatment for colorectal cancer, and 10 of their relatives, from different locations from Northern Scotland and Shetland. Data collection involved four focus groups of patients. The aim of the study was to compare rural and urban areas of Scotland. They noted that there was a lower referral rate to specialist cancer services for older patients in the rural area. In addition, patients in this locality tended to present later with more advanced disease. Rural patients had fewer expectations of services and had additional difficulties in accessing services due to lack of transportation. Thus there were lower expectations from a geographical and an individual sense.

Butow et al. (2012) carried out an international literature review to explore what is known about levels of morbidity in rural settings. Overall, studies demonstrate that disparities exist between urban and rural areas in definition and in the methodological approach undertaken. Studies within this section have been varied greatly in date of publication to scope changes through time.

This section has emphasized that the place of care is a factor which influences options and access to cancer treatment. Importantly, chronological age also brings specific inequalities in relation to treatment. While the care environment encompasses the place of care, which

[10] This study was carried out in response to the Scottish Cancer Coordinating and Advisory Committee (SCCAC) (1996).

is tangible, there are less tangible aspects of care that make a setting more supportive to cancer and/or gerontology. This will be discussed in the next section.

Specialist and non-specialist settings

To further explore the significance of the place and specialty of care, a pilot qualitative interview study was undertaken in a cancer centre (Chouliara et al., 2004b). Chouliara et al. explored older people's perspectives regarding their cancer diagnosis and treatment. Patients were recruited from a cancer in-patient centre and a care of the older person ward. It was noted that over-75-year-olds were cared for in the care of the older setting, while under-75s were cared for in the cancer specialist setting.

Patients in the older person's ward had less information and fewer options for cancer treatment, while on the cancer specialist ward older patients were more informed about their care. Professionals on both wards were paternalistic towards older people, despite patients wanting to be in control of their treatment plans.

Findings highlight that patients, while wanting treatment, also looked to their quality of life so there was a balance of personal needs with the prospect of undergoing treatment. Particular patients talked about enjoying life, not suffering in pain and not viewing cancer as a disruption of everyday life. Older patients looked to their hopes, considering care with cure, thus looking at their overall quality of life. Part of their hope was augmented with a societal trust for doctors, feeling that they always knew best.

On the other hand, findings reinforced that older patients want to make decisions about their treatment and that they may not go for the less aggressive treatment choice despite

that being the recommended suggestion based on paternalism. Chouliara et al.'s (2004b) study, although a pilot, was helpful in that it made specific recommendations for professionals about how they should approach care, assessing frailty and individual wants and expectations. It is recognized that differences in cancer site, stage of illness and setting were not distinguished between the ward areas in relation to patient experience. These distinctions would have been helpful in making recommendations for practice in different clinical settings. The sample was small within each of the wards, so transferability may be limited. However, it did suggest that further research could be undertaken to form a larger study.

Some studies highlight the role of supportive care in a specialist setting being better than in non-specialist settings. However, Rowlands and Noble (2008) explored the views of 12 inpatients (over the age of 18) with advanced cancer in an acute ward setting. The aim of the study was to explore the experience of being hospitalized and its effect on their wellbeing. Findings indicated that patients liked friendly staff and preferred to be with other patients when they were 'very ill'; findings also demonstrated that good access to social support can reduce anxiety and improve effectiveness of care. A 'patient-centred environment' for patients with advanced cancer included having fewer single rooms and allowing for patients to have contact with others. Rowlands and Noble's (2008) study differs from the aim of Chouliara et al. (2004b): the former study aimed to explore social aspects of care with professionals and to examine the quality indicators of a hospital environment which engenders a good patient experience. The latter study explored the more clinical aspects to care, relating to information giving and choices. Both studies explored the patients' responses, but from different perspectives, though of equal

significance. The importance of generating a therapeutic space has been the focus of other studies reinforcing the role of comfort through contact with others (Andrews, 2003).

While the perspectives of patients and professionals is central to the review, care interventions provide insight into the complexities of improving care when considering non-specialist settings, and professionals who are not educated to care for this particular group of patients. Gill and Duffy's (2010) literature review stated that non-specialist areas provide a challenge for care delivery for the older population with cancer. Non-specialized cancer nurses report a lack of education and training with regard to cancer care and cancer treatments, which acts as a barrier to providing quality nursing care through fear of being unable to support patients emotionally.

Summary

The geography of where a hospital is placed brings inequalities to patient care. However, this is augmented with being older which highlights further tensions for older people being given appropriate choices. The context of care and specialty of the ward brings significant challenges for care delivery whether being centred around one illness or a variety of illnesses. This is salient for the older person with cancer as no ward is specifically created for this particular group of patients in consideration of their care needs. Importantly older patients with cancer want to make decisions but there is an overriding paternalism which inhibits choice for patients. When patients are together in the same place, this in itself serves as a support but on the other hand the way nurses interact with patients is influenced by their fear of dealing with sensitive topics and saying or doing the right thing. Education for non-specialist nurses in cancer care and collaboration with specialist nurses

is essential in order that a therapeutic relationship can be generated. Therefore, there are tangible and intangible aspects to caring that are both essential to the experience and the interaction between patients and professionals.

Thus, it is salient to consider the *way* care is delivered and the importance of place and space. In addition, care delivery is based on using all forms of knowledge which are either generalist or specialist in nature. This section has presented challenging issues in relation to place, specialty and choices for patients. It has emerged that where and how professionals deliver care is important in highlighting the *dynamics* within a caring environment. These aspects are discussed in the next section.

Second major theme: psychosocial care – professionals' perspectives towards the older person and cancer treatment

This section of the review considers professionals' perspectives towards the older person with cancer. Society and health care providers continue to view older patients in ageist ways, based on their assumptions of uniform frailty and subsequent treatment intolerance. Recognition of the distinctions between chronological, biological and functional age has the potential to foster a new paradigm for research and practice (Kagan, 2008). Professional documents emphasize the need to eradicate professional assumptions in relation to older people with cancer, to recognize the practice and educational gaps in cancer care in ward settings. This is the position of the Oncology Nursing Society and the Geriatric Oncology Consortium Joint Position on Cancer Care for the Older Adult (2007), which stated 11 imperatives for health care professionals. These imperatives have

challenged the way professionals perceive older patients with cancer, looking at age beyond chronology, to include biological, functional and personal dimensions.

Theoretical papers have reflected the unique needs of older adults, acknowledging the nature of cancer, lifespan multimorbidity and the implications when considering an ageing society (Bailey and Corner, 2003; Blank and Bellizzi, 2008; Kagan, 2008). The American Society of Clinical Oncology (ASCO), ASCO's geriatric oncology web page and the National Comprehensive Cancer Network (NCCN) have set out categories of evidence and consensus to address specific issues related to the management of older patients with cancer. Recommendations include: early screening and comprehensive geriatric assessment; identifying risks and benefits of treatment; and preventing or limiting complications of therapy to enable a better quality of life for older patients with cancer.

However, despite political documents stating imperatives for care, the importance of care delivery and the challenges in various specialist and non-specialist care settings is of significance. The specialty recognizes the interactive stance in a 'live' context and that the guidelines do not always guide professionals' plans of care, rather resting on the specialty in which patients are cared for, or the emotional and educational resources (Lewis et al., 1997; Mohan et al., 2005; Puts et al., 2010).

Thus intangible notions of the context of care and the interpersonal dynamics within a ward setting bring added insight into the process of care in amongst competing demands within ward specialties. The focus of care was salient in how professionals identified and assessed needs for older patients with cancer. This will be discussed in the next section.

Focus of care

The importance of cancer and palliative care as a specialty was not always the focus of care in non-specialist settings. Gardiner et al. (2011) explored the perspectives of 58 health professionals regarding barriers to optimal palliative care for older people in acute hospitals. The study reported that professionals regarded a diagnosis of an older person with cancer as less of a priority than that of a younger person on the ward, with some professionals believing that older people have less to live for. The context of care being acute and medically-oriented was not an appropriate focus of care for patients with life-limiting illnesses[11]. Findings identified various barriers to palliative care provision for older people, resulting in a lack of choice, including alternative options for treatments and a lack of informational and educational resources. The study emphasized the influence on negative attitudes which is reinforced through the focus of care within the ward setting. Findings showed that palliative care needs were seen as a service delivered by specialists and were not seen as a focus of care within the acute setting.

Geriatricians in the same study considered that, although their specialty gave them some experience of working with the dying, palliative care was not a core component of their remit. This contrasted sharply with the views of the consultant in palliative medicine, who perceived palliative care as something that all professionals should be able to manage. Another perception was that older people had 'a good innings', resulting in the perceived

[11] The more appropriate focus of care would be on 'continuous palliation' and managing quality of life issues.

insignificance of a cancer diagnosis. A reason for this perspective could be that ageism is intertwined in society and infused within professionals' practice. This has been noted in several studies relating to nurses' attitudes towards cancer patients (Corner, 1993b), and other health care professionals' responses and the way older patients are assessed for treatment (Cyr et al., 2011; Kearney and Miller, 2000; Kearney et al., 2000; Foster et al., 2010; Crooks, 2001; Derby, 1991).

Kearney et al. (2000) evaluated oncology health care professionals' attitudes towards older people. A survey design was adopted using the Kogan Old People scale (KOP), which was given to 197 professionals in a cancer centre. The KOP is a 34-item Likert type scale with 17 matched positive and negative statements. McLafferty (2007) has suggested that the scale measures societal attitudes but does not take into account the particular context in which professionals care for older people, which is salient, as Kearney looked at professionals in different ward contexts.

There was a varied response rate of 21% doctors, 78% nurses and 16% radiography staff. Results demonstrated that professionals had a negative attitude towards older people with cancer, which resulted in a lack of choice and access to treatment. The overall negative attitudinal scores could be a result of exposure to frail and infirm older people in the hospital setting which may have skewed accounts if healthier patients were selected. Due to the lack of differentiation between gender and/or clinical experience of participants, Kearney proposed that ageism is a result of broad societal cultural stereotypical views. While this is an important study for professional practice, there are limitations to its generalizability, as the sample was recruited solely from a cancer centre. There was little differentiation as to any differences in perspectives between or within professional groups.

There is more recent research which suggests that age discrimination still prevails (Department of Health, 2012a, 2012b). Clinicians have raised concerns that assessing older patients often does not provide sufficient information to make an appropriate cancer treatment recommendation and that collaboration with the patient and other professionals is essential for care planning (National Cancer Action Team, 2011). This is discussed in the next section.

Interdisciplinary collaboration

Foster et al. (2010) assessed the impact of age on cancer treatment decisions from 200 oncologists, through a survey based on vignettes illustrating four detailed cancer patient cases. The survey was modified so that an equal portion of respondents would decide on a treatment approach for two younger and two older cancer patients. Multiple-choice responses of treatment selection and open-ended responses for factors involved in this decision were analysed to test the hypothesis. Findings demonstrate that oncologists are less likely to recommend intensive, but beneficial, cancer therapies to older adults. Treatment planning for older adults must look beyond simply chronologic age and should consider multiple indices of health as well as patient resources to support the cancer treatment process.

A qualitative study focusing on interdisciplinary working was conducted by Puts et al. (2010). The aims of the study were to explore the perspectives concerning collaboration between cancer specialists and geriatricians and to highlight the challenges in collaboration between specialties. A total of 44 (24 cancer specialists and 20 geriatricians) agreed to participate. Qualitative interviews explored collaboration between oncologists

and geriatricians, and their research priorities for older people with cancer. Results included ten main domains. In relation to assessment, oncologists used a standardized assessment tool, using the ECOG[12] and Karnofsky Scale[13]. Cancer specialists stated that the management for patients was the same for young and old, although some reported older patients had more toxicities. However, communication with older people differed from that with younger patients. Older patients were perceived as less demanding, but as having fewer resources and commonly living on their own, which added to their social unmet needs.

Geriatricians stated that they did not follow up on patients after chemotherapy due to the lack of staff with the expertise in chemotherapy, though they reviewed patients who were receiving radiotherapy. Similarly, oncologists did not refer their patients to geriatric medicine unless they needed to assess cognitive ability. Surprisingly, about half of geriatricians mentioned that patients refused to see a cancer specialist. Overall, the collaboration between cancer specialists and geriatricians was limited and at times non-existent.

Another major theme in Puts et al.'s (2010) study related to the challenges in interviewing older patients, including time spent in the assessment of multimorbidities, listing medications and evaluating social networks. Older patients were also admitted for

[12] The ECOG includes scales and criteria that are used by doctors and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis.

[13] The Karnofsky Performance Scale Index allows patients to be classified as to their functional impairment. This can be used to compare effectiveness of different therapies and to assess the prognosis in individual patients. The lower the Karnofsky score, the worse the survival for most serious illnesses.

treatment to hospital rather than being at home, due to a lack of social support and access to transport. Both specialties indicated a need for more support systems during cancer treatment. Oncologists also mentioned the lack of clinical trials for older patients. The strengths of the study are that the qualitative approach provides an opportunity to explore opinions in a more detailed way, which gives an in-depth perspective of the relational and contextual meanings of data (Seale, 2004).

The need for an interdisciplinary approach to assessment and care planning is vital (Puts et al., 2010). Importance is placed on clinical nurse specialists and the nurses' role emphasising frameworks for education and practice (Royal College of Nursing, 2012). The importance of integrative working is also dependent on educational and emotional competence to enable supportive care (Royal College of Nursing, 2002a, 2002b). It is also suggested that the role of clinical nurse specialists is to improve productivity and capacity within cancer services (Scottish Government, 2007, 2008a, 2008b, 2008c). Recent research has reinforced the need for collaboration of cancer and geriatric services from an interdisciplinary perspective (Kagan, 2009; Puts et al., 2010*).* The constant dynamic between patients and professionals reinforces the interconnectedness of the social world within the ward setting. The components of place and space are to be discussed in the next section.

Place and space

The notion of place and space emphasizes that the ward environment's characteristics, such as spatial and social features, influence physical and psychosocial interactions between patients and professionals (Andrews, 2003). This was particularly relevant when

patients were admitted to the same clinical area especially in the context of cancer and palliative care (Kelly et al., 2004).

Glaser and Strauss (1965) suspected that the notion of space and place were a key to understanding the interactions between those people when they explored the expectation of death by both the dying and their relatives. Their choice of hospitals and stations allowed them to compare various kinds of expectations. On a premature infant station, mortality was high but the patients were not aware of their impending deaths, while on an oncology station, dying was slow and differences in the awareness of dying were very pronounced. The typical situations were again different for emergency rooms and geriatrics or paediatrics departments.

Out of these field studies grew ‘Awareness of Dying’, a theory on the influence of awareness on the interaction with dying people. It differentiated between closed awareness, suspicion, mutual deception, and open awareness. The field studies had shown that the type of awareness had a significant impact on interaction – for instance, if patients were not aware of their dying, the nursing was often limited to the absolutely necessary in order to prevent open awareness.

Nurses try to protect themselves from distressing symptoms by distancing themselves physically from dying patients. Consequently, nurses may locate dying patients in side-rooms and hand over part of their caring role to relatives (Sudnow, 1967). In addition, Menzies (1960) explained impersonal care to be the result of nurses’ work organized unconsciously to protect themselves against anxiety. Field (1989) engaged in participant observation and interviewed nurses working with dying people in different clinical

settings. He found similar to Menzies (1960). Field argued that ‘detached concern’ was detrimental to patients and was the consequence of inadequate staffing levels, low levels of reward and a lack of support in coping with stress. He claimed that all these structural factors make it impossible to give holistic care. Another proposition is that emotional labour is unsupported as seen as a gender related job for females, and is not recognized by others (Theodosius, 2008). Studies have also shown that ‘detached concern’ was prevalent with older patients particularly with older people in comparison to younger people. To help emotion management it is important for collaboration between specialist and non-specialist nurses as non-specialist nurses are often ill equipped to deliver care to older patients with cancer as they are challenged by a lack of resources and emotional demands. This is discussed in the next section.

Professional care: specialist and non-specialist nurses

Some studies have focused on care delivery from general[14] nurse roles (Mohan et al., 2005) and specialist roles (Lewis et al., 1997). Mohan et al. (2005) described the experiences of nurses caring for cancer patients in two non-specialist wards. The study was conducted in a large 420-bedded hospital and in a small 32-bedded area in another hospital. Both hospitals housed patients from urban and rural populations in Sydney. Data were collected using surveys and semi-structured interviews. The return rate was poor, with only 25 surveys returned (50%). Only five nurses consented to be interviewed. The six major themes identified within the non-specialist settings were: the emotional nature of

[14] General nurses are those who are not trained in a specific specialty of care such as oncology or care of the older person.

care, lack of time, lack of knowledge of cancer treatment, time to give patient and family support, environment as not conducive to care and dealing with patients' non-acceptance of cancer diagnosis. In this study, *general* nurses seemed to find it difficult to deal with the emotions of patients and their family, often not knowing what to say to patients. Nurses also found a lack of time to give emotional care due to an increasing workload (this was most prevalent in the medical ward). They felt they did not have appropriate education on symptom management, especially relating to pain management. There was also intra-professional tension, where doctors were reluctant to give analgesia at the appropriate dose. Psycho-social tensions related to dealing with patients being in denial and who refuse treatment such as analgesia. Recommendations are to provide more education in communication, how to deal with emotions and symptom management for professionals.

This is a significant study, as it demonstrates the need for support for non-specialist nurses in cancer care. Strengths are that semi-structured interviews allowed for an in-depth exploration of sensitive topics which may have been lacking in the survey results. Limitations were the poor return of the survey, but the qualitative nature of the interview gave insight into the deeper challenges to caring. It is also unknown who returned the questionnaire (what grade or education). It is unknown what five nurses were interviewed, where they are based and what educational background they had. While the study does not discuss particular needs of older patients with cancer, its findings can be transferable to general nurses. It also identifies a gap in research which considers the interaction between professionals and older people in non-cancer ward settings.

Lewis et al. (1997) explored the types of decision-making encountered by older patients with cancer and/or their family caregivers, requested and required within one practice

setting. Semi-structured interviews were conducted with five cancer centre nurse coordinators (CCNCs). The CCNCs were interviewed weekly for 16 weeks to identify decision-making topics addressed, assistance requested, and perceptions of assistance required during telephone conversations from older people or their families. The CCNCs' reports of 41 telephone conversations revealed 44 specific decision-making topics. Content analysis uncovered 11 categories: symptom management, use of chemotherapy, ancillary choices, selection of a medical provider, planning for end of life care, alternative therapy, vacation planning, weekend-pass planning, discharge planning, family survivor issues and involvement of adult children in the elder's care. Older patients and their family caregivers requested information and assistance with making decisions about their care. CCNCs perceived that callers had a range of needs including clarification, reassurance about their decisions, a listener, and permission to change the treatment regimen and help with communication among health professionals. Interestingly, the highest number of calls was from female patients, with 34% living alone.

Lewis's study has highlighted the importance of specialist nurses in supporting older cancer patients while at home. Limitations are that, due to the telephone conversations, the observation of non-verbal behaviour that may have alluded to other issues such as pain or need for other supportive interventions were lost. It is also unknown if the CCNS knew the patients, which may have influenced patients' disclosure, or whether the responses to calls were coordinated and teamed with prior therapeutic knowledge.

These two studies were included within the review, as they contrast abilities of professionals when dealing with psychosocial care. Lewis et al.'s (1997) study

demonstrates the wide-ranging aspects of supportive care for these patients from the domains of social support to symptom management in primary care. Mohan et al.'s study (2005) highlighted the organizational and educational aspects to care which hindered the ability to care for this group of patients. The general nurses did not feel equipped to care for the emotional needs of patients, while Lewis's study found that specialist nurses have a key role in delivering specialist supportive care. Dealing with psychosocial challenges was seen as a challenge for general nurses in a general ward. However it could be argued that this could be due to the face-to-face interaction and the challenges of dealing with the emotional problems of patients. In Lewis's study, talking over the phone may have psychologically protected the nurses from an emotional engagement that Mohan's study highlighted. In addition, the lack of education in cancer care may have further impacted the professionals' ability to deal with patients' emotional issues.

Sahay et al. (2000) interviewed (via telephone) 20 patients (48 to 87 years) who attended a gastrointestinal follow-up oncology[15] clinic in Toronto. Overall, patients were satisfied with their treatment, including the quality and timeliness of the information they received, the quality of their healthcare, and their level of involvement in decision-making. However, some patients were dissatisfied with information concerning the long-term management of their illness. Patient care, including information and social support, was provided by cancer specialists, family physicians, family, and friends. Patients looked to cancer nurse specialists as their primary source of information: to provide support, to

[15] Oncology is the medical study and treatment of cancer. A physician who practises this operation is called an oncologist. The term oncology is from Greek word "onkos" which means mass, bulk or tumour, and the suffix "ology" means study of.

manage overall care and to act as a sounding board for ideas and treatment options. While some patients acknowledged difficulty in coping with the side effects of treatment, older patients' quotes demonstrated particular resilience in 'getting on with life', and protecting family emotions. Older people emphasized the need for 'truth-telling' and provision of information in order to minimize uncertainty.

This was in contrast to Bain and Campbell's study (2000), which included older people who did not want information but presented later in their illness. However, patients in Sahay et al.'s study (2000) were all at a curative stage in their cancer treatment, having had surgery or having completed radiotherapy or chemotherapy treatment. It appears from both studies that the stage of illness is central to how people react to their illness. The sample in Sahay's (2000) study had all undergone surgery and some had also been treated with radiotherapy or chemotherapy. They were treated in a clinic area which was solely dedicated to the specific specialty. The stage of the cancer may have engendered a more positive approach to their illness, as all were being managed through active treatment (all patients in the sample were of a similar stage with a diagnosis of colorectal cancer). From a data generation perspective, having one interview over the telephone may have been insufficient for revealing the patients' deeper concerns. Also, their emotional needs might have been different if they had had another cancer diagnosis and/or in the palliative care stages, as illustrated in Duggleby et al. (2010).

Studies (Sahay et al., 2000; Puts et al., 2010; Mohan et al., 2005; Lewis et al., 1997) highlight the need for holistic care from different professional perspectives. Recommendations relate to health care policies, emotional engagement and

communication between professionals and with patients (Sahay et al., 2000; Puts et al., 2010; Mohan et al., 2005; Lewis et al., 1997). This has also been demonstrated in other studies and theoretical papers (Corner, 2002; Corner and Bailey, 2001). Clarity of roles within a specialty is central to the coordination of care delivery. Ensuring that individual needs are listened to with professional clarity and that appropriate beliefs are integrated into care delivery is of utmost importance. Some research studies have stated that clarity of beliefs comes through education which develops professionals' awareness of needs for this particular group. This will be discussed in the next section where studies in relation to the education of non-specialist staff will be critiqued.

Education

In clinical practice, a non-specialist workforce, including a whole range of health professionals, provides a large proportion of care to older patients with cancer. There have been many studies which have explored the perceptions of professionals. Some studies have focused on nursing staff (Mohan et al., 2005; Hockley et al., 2005; Froggatt, 2000a, 2000b, 2001a, 2001b), while Wood and Ward (2000) chose a qualitative approach to explore all professionals' perceptions of education in cancer care. The sample in Wood and Ward's (2000) study included both specialist staff and non-specialist staff within two health authorities in London. Specialist staff needed to work in a specialist area and had post-registration qualifications in oncology. Non-specialists worked in a non-specialist setting and had no post-registration qualifications in cancer care.

Three focus groups and 13 semi-structured focus groups were conducted with specialist staff including cancer nurses, a hospice director, occupational therapists and GPs.

Eighteen focus groups and ten semi-structured interviews were conducted with non-specialist staff and included community staff, radiographers, a chaplain and ward nurses. Findings showed six areas of educational needs that were identified by both specialist and non-specialist staff. Patients also identified six of the areas. Areas of training included issues related to cancer, effect of treatments, communication, dealing with difficult questions, caring for patients with Hickman lines, pain management, feeding and nutrition issues and death and dying.

Differences between specialist and non-specialist views related to knowledge of cancer treatment and communication skills in that the non-specialist staff had particular fears of talking to patients with cancer. Non-specialist staff felt that they were unable to give appropriate care due to their lack of education. Patients also reiterated these findings. Specialist staff felt that non-specialist staff should have more training in communication skills. This study benefits from a wide sampling pool, which generated a breadth of information relating to the educational needs of both specialist and non-specialist staff from a combination of sources.

More specifically in relation to non-specialist nurses, McCaughan and Parahoo (2000) aimed to survey medical and surgical nurses in a district general hospital in Northern Ireland. The sample consisted of 106 nurses to assess the profile of medical and surgical nurses and a self-reported level of competence in a number of activities relating to their work with cancer patients. A 15-item self-rating scale was used with a 23-item checklist (adapted from Corner and Wilson-Barnett, 1992). This study's strengths in data gathering relate to the free text and Likert scale used to gauge responses of nurses. The tools were also validated prior to the study. Of the 73 nurses who responded, 42 were medical and 30

were surgical nurses. Both medical and surgical nurses reported the need for more time to give holistic care. It was also reported that more knowledge was needed in relation to pain relief and ethical dilemmas. Respondents reported competence in giving physical care, but felt less adequate in dealing with emotions relating to patients' illness. Care domains were perceived to be dealing with social and psychological problems (69.4%), dealing with symptoms (65.3%), side effects of treatment (62.5%) and death and dying (61.1%). The main findings were that nurses in a district general hospital have an important contribution to make towards the well-being of patients with cancer. Both these studies demonstrate the lack of information for non-specialist professionals and why it is of importance in clinical and psychosocial domains. Strengths of both studies were the transferability of findings indicating non-specialist educational needs.

Froggatt (2000b) carried out a palliative care educational project over two years, in which staff from 54 care homes in England took part. Courses were designed for registered nurses, healthcare assistants and ancillary staff. The courses included a 12-day course for trained nurses, a 7-day course for healthcare assistants, and a 1-day course for ancillary staff. This educational project was unique in that it catered to all levels of staff. The evaluation revealed significant individual learning in relation to dealing with symptom management and coping with emotional issues in relation to care. However, when staff returned to their respective care homes, they found it difficult to effect change (Froggatt, 2000a). The fact that the educational courses were delivered outside of the care homes may have weakened the impact on the ward as it did not acknowledge the culture in which professionals work which has been significant in other studies (Mohan et al., 2005; Hockley et al., 2005).

The particular strength of Hockley et al.'s (2005) study, previously discussed, was that staff gave more of an in-depth response, having been interviewed through semi-structured interviews and focus groups that allowed for more expression in relation to the context of care they were in. Including professionals from throughout the ward could be argued to have encouraged teamwork in itself and promoted the significance of the responsibility of all roles to deliver effective palliative care. The methodologies were contrasting, as action research used in Hockley's study allowed staff to learn in action, while learning through questionnaire and educational courses during Froggatt's study did not facilitate education into practice. The contrasting of Froggatt's and Hockley's study brings into sharp focus the need to consider the context of care and how older people are being cared for.

A study relating to care interventions (Hockley et al., 2005) looked at the introduction of a care pathway within eight care homes. This study was chosen as demonstrating that good palliative care can be provided in a non-specialist setting following practice development and that the nursing role is integral to the improvement of care delivery in palliative care.

Hockley et al. (2005) explored end of life care for older people in eight independent care homes. The action research study aimed at evaluating the implementation of an 'integrated care pathway' (ICP) as a way of developing quality end of life care for older people. This study was part of a larger study which aimed to explore the care delivery to older people in care homes (Bridges Initiative, 2004). Data collection included case notes of residents, end of life medication prescribed and interviews with relatives and nursing home managers, which included eight nursing home managers and three nurses, with one being a specialist in palliative care. Group interviews were attended with trained staff and care

assistants. The Culture and Care questionnaire (Bate, 1994) was also completed to explore the organizational culture.

Findings identified five main themes. These were a greater openness around death and dying following the introduction of the care pathway, recognizing dying and taking responsibility, better teamwork and critically, using palliative care knowledge to influence practice and facilitate more meaningful communication. Key recommendations were to recognize death and dying in care homes and the need for education and diagnosing dying. Findings demonstrated that nurses have a real opportunity in promoting quality end of life care and initiating end of life medication. Finally, introducing an ICP for the last days of life can enhance quality of end of life care. This study was helpful in stating the importance of understanding the context of a non-specialist setting, as well as identifying professionals' emotional tensions in caring for older people with palliative care needs.

The aim of the study, to explore end of life care through the implementation of an ICP, was attained through the appropriate methodology of action research, which enabled the teaching of professionals while gathering the data. Findings were also contextual in how care could be improved (through education, communication and documentation). Limitations of the study were that the findings may not be wholly transferable to cancer care settings, but would be transferable for both non-professional and professional carers. Findings highlighted that nurses felt more in control of end of life care, acknowledging the diagnosis of death through an ICP. Hockley's work was based on the findings from previous research on education in a non-specialist setting, perceiving that education is only part of the solution to improving care for this group of patients (Froggatt, 2001a, 2001b).

Other studies were selected to highlight the role of health care professionals, especially general and specialist nurses in supportive care[16] for older people (Sahay et al., 2000; Hockley et al., 2005). Further studies were chosen to demonstrate how the active management of cancer can alter the coping strategies of older people and lead to being more positive rather than more hopeless (Sahay et al., 2000). Other studies have shown the benefit for patients in being in a specialist ward and having more information and choices for treatment. As well as being in a specialist setting 'place' has been argued as causing an impact on care experiences (Andrews, 2003; McCormack and McCance, 2010). Patterns of decision making, power differentials, the focus of care, are all said to be components which make up the 'context'.

Summary

This section has discussed professional perspectives towards care delivery and the related attributes that promote effective care delivery. Literature suggests that the focus of care without interdisciplinary collaboration generates an emphasis on some aspects of patients' needs while other aspects are less of a priority. Whether there is an emphasis on cancer and/or the older person affects the care patients receive. In addition to the focus of care, the roles which professionals encompass is influenced by the active interaction with patients and the shared meaning that is generated between professionals and patients within care environments. Education is an attribute which is of importance to inform care

[16] Supportive care is given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social and spiritual problems related to a disease or its treatment.

delivery and so allow practitioners to have the required expertise and competency to deliver care. However, to appreciate the educational needs of professionals and to recognize the person behind the patient it is important to consider the biographical characteristics of the person. This will be discussed in the next section.

Third major theme: biographical characteristics

The organization of literature has purposefully been arranged to demonstrate the spectrum of person-centredness from the macro to the micro. This next section discusses the individual, more micro attributes of being older and the significance in changes to treatment and emotional support. The social construction of gender also constitutes a social force which is believed appropriate to the way patients convey their perceptions of need. The experience for patients of having certain cancers is also compared and contrasted.

A number of studies have placed emphasis on the way older people cope with cancer, demonstrating that there are particular strategies used in comparison to their younger counterparts (Harrison and Maguire, 1995; Walker et al., 1998). Harrison and Maguire (1995) interviewed 520 patients aged between 18 and 75 years old within 8 weeks of diagnosis, using a 14-item checklist questionnaire. Patients had a diagnosis of various cancers such as breast, bowel, gynaecological lymphoma and testicular. Results showed that older patients were significantly less concerned about the illness itself, but wanted more information about treatment being provided, and the effect it would have on relationships with partners.

Harrison and Maguire (1995) concluded that younger patients have greater difficulty dealing with their diagnosis and that older people tend to look at their illness within the context of their lives mostly lived. Recommendations are that particular attention should be given to the practical issues of older patients such as transport to hospital, and financial support. This finding is important, as it implies there are additional difficulties experienced by older people, such as living alone. This reinforces the impact of ageing and social isolation and the importance of social interaction. The age range covered by this study was up to 75 years old. It would have been helpful to include a larger age range encompassing older patients who are above 75, thus representing the greater percentage of the cancer population. The patients included in this study were all within 8 weeks of diagnosis, but it was not identified if this time frame had an influence on their coping patterns and if their disease brought particular challenges in comparison to other diseases. In particular, given the range of cancers covered by this study, it would have been helpful to explore if there were particular aspects to patients' disease in the context of multimorbidity, which is relevant in the older age group (Extermann and Hurria, 2007).

Another comparative study, Walker et al. (1998), undertook a questionnaire study of 80 patients with breast cancer who were admitted to a hospital for staging, the age range being 35 to 91. The main aim of the study was to assess the relationship between age and patients' views regarding the extent to which psychosocial and biological factors should be taken into account in clinical management decision-making. The results showed a striking similarity in the views of both older and younger women relating to wanting the most effective treatment regardless of side effects and the amount of time and distance to hospital. Both groups wanted treatment that was best for them, not the regime that caused

fewer side effects or fewer admissions to hospital. In addition, both age groups wanted to be informed of the details of their disease, likely side effects and different options for treatment. This study supports the need for professionals to give appropriate information regarding patients' options. This study's findings contrast to those of Harrison and Maguire (1995), since it suggests that age is not relevant when considering decision-making about treatment.

Older populations have distinctive characteristics due to the process of ageing (Avis and Deimling, 2008). The combination of ageing affects their psycho-adaptive responses (Trask et al., 2008). Older populations with cancer are also subject to an increase in symptoms such as depression, fatigue and pain, which affect their psychosocial response to illness (Rao and Cohen, 2004; Drayer et al., 2005; Duggleby, 2000a, 2000b). There is a need to consider the holistic picture of older people confronting multimorbidity[17] and other social problems of 'being older' such as living alone or being physically and emotionally more vulnerable (Hall et al., 2003; Given and Given, 2008, 2010). Current patient clinical assessment tools which focus on particular aspects such as functional status are criticized for being too narrow and do not reflect the true clinical picture of the older person. Functional status measurements commonly used in oncology, such as the Karnofsky Performance Status (KPS) and Eastern Cooperative Oncology Group performance status (ECOG), have recently been challenged by professionals as to how

[17] One of the greatest challenges in health care is providing optimal care for older adults with multiple chronic conditions, or 'multimorbidity'. More than 50% of older adults have three or more chronic diseases (Long-term Conditions Alliance Scotland, 2008). The heterogeneous patterns and severity of conditions produce distinctive cumulative effects for each individual (American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity, 2012).

adequately they reflect the true clinical picture of the older person (Begg and Carbone, 1983; Puts et al., 2010; Repetto et al., 2003; Balducci and Beghe, 2000; Lewis et al., 2003). Repetto et al.'s (2003) study states that functional status measurements overestimate an older patient's ability. Thus assessment tools only go part way is assessing the needs of older people with cancer.

While age-related coping adaptations to multimorbidity affect the way older patients perceive and cope with their illness, it is important to also consider gender adaptive responses, which give further insight into the social construct of a person and their consequent understanding of how they manage their illness.

Gender-related adaptive issues

Gender-related adaptive issues have been discussed in two studies included within this review which highlight distinct differences in how males and females deal with their illness (Thomé and Hallberg, 2004; Bungay and Cappello, 2009). The perspectives of masculinity and femininity constitute a social force in the experience of ageing and living with cancer. Moreover, it is important to recognize how gender and ageing affect the experience of and response to cancer. It is seen as an attribute which conjures up social expectations and duties within society (Phillips et al., 2010). Men and women differ as to life opportunities and experiences which shape situations in later life, such as family care giving and work demands. The experience of ageing is influenced by various losses and transitions, such as loss of family and spouse. Women have been regarded as more vulnerable, as they live longer and may have more incidences of loneliness, increased multimorbidity and isolation (Thomé and Hallberg, 2004). How different genders deal

with their cancer diagnosis is therefore significant when professionals consider specific supportive care interventions.

A study by Thomé and Hallberg (2004) was chosen to illustrate quality of life in relation to gender. It was a comparative study, with the inclusion criteria aged 75 and above and a cancer disease, and a matched comparison group of women (n = 64) and men (n = 74) without cancer. The study used the EORTC QOL-C30 questionnaire. The EORTC QOL-C30 questionnaire was developed by the European Organization for Research and Treatment of Cancer. Five functional (physical, role, cognitive, emotional and social functioning) and three symptom scales (fatigue, pain, nausea and vomiting) are included. There was also a sense of coherence scale (SF-12) which was intended to measure individuals' general understanding of their life situation. The sample included cancer diagnosis within the past ten years, which represented people with relapse or with remaining side effects of treatment.

Findings relate to functional status and demonstrate that women more frequently reported oedema and sleep disturbance, whereas incontinence was a problem experienced more often by the men. Women were more likely to report feelings of loneliness and fear than were men, and were also living in poorer economic situations than their male counterparts. Pain seemed to be felt equally between men and women. Overall, women were more vulnerable than men in both a physical and social sense. This study was informative, as it covered many domains of life and had a large sample, including various cancers, which increases the generalizability of the findings. However, due to the large sample there may have been less attention to individual lifestyle, social support and care giving, which could have given more insight into women's loneliness.

Psychologically, men tended to be pragmatic about their illness and the need for help, whereas women perceived help as an intrusion into their privacy. The findings highlight the importance of gender in older people's coping strategies. Differences in findings between genders were particularly helpful when using the SF-12, which demonstrated that the strain of illness is more prevalent in women than men. Multimorbidity is also attributed to a poorer quality of life in both sexes. It was unclear if the accounts of pain were due to the cancer or multimorbidity. Strengths of the study were that the sample involved older people living in their own homes, which gave insight into older people's life worlds. Limitations of the study were that the sample represented the healthier subgroup of the population who were able to complete the questionnaire. In contrast to comparison of genders using a large study, Bungay and Cappello (2009) recognized the significant worldwide health problem of prostate cancer and how this significantly affects older men by the time they reach 80. The aim of this study was to explore information and support needs of men aged 75 and over. They conducted 19 in-depth semi-structured interviews to explore why older men did not seek information relating to their cancer. Bungay and Cappello's (2009) methodology encouraged open, reflective and informative responses. This facilitated exploration of the context surrounding participants' responses. Purposive sampling identified men over 75 from a urology outpatient clinic. Findings were that men do not access help lines or request information as they cope on a daily basis. Some did not understand the treatment they were having (hormone therapy) as information was not readily understood. From a societal perspective, participants perceived cancer as life-threatening and were therefore afraid to seek information. Trust in professionals' decisions was also another reason why men did not ask for information. Participants tended to perceive doctors as authoritative and thus were unwilling to

question information they received. This study gave a deeper insight into older people's perspectives of their illness, considering the intersection of gender, age and prostate cancer. These findings are in contrast to studies of women who are older with cancer: men remain more reticent in seeking choices and options for future care.

Women appear to be more emotive in their feelings, looking to protecting their families while dealing with their own emotions. They also appear to seek information and treatment options (Sinding and Wiernikowski, 2008). These studies (Bungay and Cappello, 2009; Thomé and Hallberg, 2004) were important in exploring deeper social constructs of ageing and gender than was given in prior studies (Bain and Campbell, 2000; Sahay et al., 2000; Chouliara et al., 2004b). While the attributes of age and gender are important in understanding life course, the next section considers psychosocial adaptations in relation to older people with various cancers, which is explored from a theoretical and empirical stance.

Older people with specific cancers

Bury's seminal study into disruption and chronic illness has been of interest to many researchers who studied older age and chronic illness (Faircloth et al., 2004; Hubbard et al., 2010)[18]. A number of studies have applied Bury's theoretical framework, demonstrating its usefulness in exploring the specific adaptive responses to particular cancers, since it allows researchers to study how cancer is related to life course and social

[18] Biographical disruption is a theoretical framework developed by Bury (1982) in relation to patients diagnosed with rheumatoid arthritis. Through their experiences, it was identified that patients attempted to separate themselves from the past and how they feel now. They attempted to incorporate the changes through a mobilization of emotional and physical resources, re-conceptualizing the past, present and future (Bury, 1982).

identity (Hubbard et al., 2010; Sinding and Wiernikowski, 2008; Pieters and Heilemann, 2011). Two of the studies offer evidence to suggest that a long life characterized by old age and hardship renders cancer unproblematic, disputing Bury's theory of biographical disruption (Bury, 1997) when applied to this age group (Hubbard et al., 2010; Sinding and Wiernikowski, 2008).

These articles were chosen as they focused on the psycho-adaptations of older people with cancer and used Bury's theory of biographical disruption. The application of Bury's work in their analysis demonstrated that their diagnosis was not disruptive (Hubbard et al., 2010; Sinding and Wiernikowski, 2008). Both studies suggested that in comparison to past lived events, a diagnosis was continuous to their life course. Samples included all females (Sinding and Wiernikowski, 2008) and mixed genders (Hubbard et al., 2010).

Hubbard et al. (2010) used a qualitative longitudinal approach to explore the experiences of 18 people with colorectal cancer. The age range spanned from 31 to 85, with the majority being between 61 and 85 years old. The sample was both male and female. The sample inclusion criterion was that participants had to be within one year of diagnosis. Hubbard et al. used the theoretical framework of Bury (1982) and Charmaz (1983, 2002)[19] as a descriptive and explanatory theory to understand how people respond to their illness. Findings highlighted the impact of social isolation, including themes of loss of self, while other participants had disrupted lives with a loss of identity. The study also considered the

[19] Charmaz (1983) used the phrase 'loss of self' with her research in the 1980s. She describes the loss of self as developing from chronic conditions and the illness experience. This restricted life is experienced through social isolation being discredited and burdening others.

theory of 'hard-earned lives'[20] and that some patients may not see cancer as disruptive or as a threat to identity (due to multimorbidity and past life events). The study explored experiences over a period of time, which allowed for development of understanding about the temporal dimensions of accounts through comparing and contrasting accounts over time. This longitudinal study helped gain insight into the discourse of living with cancer over a period of time. Limitations are that the study only looked at patients up to one year of diagnosis with colorectal cancer and so the findings may not be transferable to other cancers with a longer diagnosis. The younger members of the sample were able to continue working. Interestingly, older patients found their diagnosis equally undisruptive, but for different reasons. Reasons given were the already hard lives older people had experienced, which could be argued to blur rather than negate the impact of the illness. The theoretical stance which underpinned the study was symbolic interactionism, which rested on identity being based on what the self sees as themselves.

Sinding and Wiernikowski (2008) challenged Bury's (1982) notion of chronic illness as a biographical disruption, arguing that, in the context of certain life circumstances, such as having multimorbidity, chronic illness tended to be perceived as normal. The 'normal hardship theory' has gained credence and underpins the argument that a cancer diagnosis is just as or not as significant as other problems, thus chronic illness is not so disruptive. The study explored social circumstances and how this affected women's quality of life. The sample included women diagnosed with breast or gynaecological cancer over the age

[20] Cornwell (1984) suggests that illness should be considered in relation to the greater picture of their 'hard-earned lives'. This has been further reiterated in more recent studies by Harris (2009) and Pound et al., (1998).

of 70 to 80-plus. Of the 16 interviewed, 10 had breast cancer and six had gynaecological cancer. The patients were all interviewed in their homes or in breast cancer support services.

Some participants felt that having a diagnosis of cancer was expected at their age. Similarly, some participants represented the loss of organs such as their breasts or womb as unproblematic because they were no longer of child-bearing age (Sinding and Wiernikowski, 2008). This study highlights the multiple identities that people deploy to manage their illness. Strengths within the analysis of data were through the constant comparison method, which looks for negative cases which are seminal to the building of theory. This approach adds rigour and a systematic approach to the generation of data.

Both studies acknowledged that past health and social life experiences of participants may generate a process of 'normalization' when considering their diagnosis. Hubbard et al.'s (2010) study proposed that participants' past suffering blurs the impact of their illness rather than makes it continuous.

Another study which focused on the experience of breast cancer in old age, Pieters and Heilemann (2011) explored older (70 to 94 years) breast cancer survivors' perception of the term 'survivorship' and what meaning it held for them. This study was chosen as it not only focused on older people with cancer but identified the comparison of oneself to others as a coping strategy. This suggests that the social interaction of the older person with cancer is as important as considering one's own past life events. This study also gives support for the ontological position of social constructionism as a useful theoretical framework emphasizing interaction between people as a way of generating knowledge.

Findings included that women did not always see themselves as cancer survivors. Having lived for many years, participants referred to their established identities prior to being diagnosed. Prior identities were more important than a title of 'survivor'. Comparison to others also helped as a strategy to facilitate acceptance of having cancer and being old, thus acknowledging social interaction as a way of coping. This study's findings were consistent with those of other studies (Sinding and Wiernikowski, 2008; Hubbard et al., 2010) in that it found that cancer did not always change the lives of older people, often being seen as biographical continuation rather than disruption.

Summary

Overall, being older has an impact on patients' psycho-adaptation to cancer as well as the clinical manifestations of their illness. Studies related to psychosocial adaptation have demonstrated how older people have distinct coping processes related to their individual life course which make them unique individuals while also embracing societal representations of being old. Thus, the interlinking of the cancer diagnosis with past experience, gender and social ageing brings an interplay of factors to strengthen the argument that caring for the older person should be holistic. Identifying how older people with cancer are perceived portrays a complex picture, with themes of feeling deserving or undeserving of appropriate care, and normalizing their illness, yet living with uncertainty. These conflicting values for older people with cancer make appropriate care a challenge, as they appear to battle for their individuality within the context of a health care system. Supportive care delivery needs to be explored, to indicate the influencing care interventions which enable older people to adapt to their illness.

Methodological limitations of the literature review

There were many studies from different parts of the world such as Italy, the USA, and Britain, which may have limited the transferability of the findings to Scotland, as health care services are different in their organization of cancer and palliative care services. There was a lack of research relating to the gerontological perspective of cancer and ageing. The current research considered in the review had more of a focus on locality or gender or disease rather than considering all issues. The most neglected part of understanding the cancer and ageing interface is the broad area of 'growing old' and living with cancer (Blank and Bellizzi, 2008).

Samples aimed to capture age differences between older patients and their younger counterparts (Walker et al., 1998; Harrison and Maguire, 1995; Sahay et al., 2000). Some studies explored the psychological needs of older people by comparing them to younger patients with cancer (Harrison and Maguire, 1995; Walker et al., 1998). While this is helpful, comparing to a younger age group solely on the basis of age may not represent the true picture of psychosocial adaptations which individuals experience. There was a lack of consistency in the research regarding particular aspects of the older person (such as gender or cancer type in relation to age). As a result of the wide variability, the process of comparison and contrasts were made within small clusters of articles. Age was perceived as a sampling tool, rather than looking at qualitative data which considered the social construction of age and how it influenced care decisions from a broader health care and individual perspective. Studies instead looked at outcome measures, such as whether treatment was given or not (Pitchforth et al., 2002). Some studies which were more qualitative in exploring patients' needs were small in sample size and were not

transferable (Chouliara et al., 2004b) or considered age within a country which had a different social and health care context (Sinding and Wiernikowski, 2008).

Gender was considered in few studies and was mostly related to females (Hubbard et al., 2010; Sinding and Wiernikowski, 2008). There was only one paper reviewed which focused solely on men (Bungay and Cappello, 2009). This was also in relation to prostate cancer, indicating a lack of research relating to how older male patients cope with the impact of cancer. Overall, this was important, as the generation being researched was of a certain historical time.

The meaning of growing older was important to how older people adapted to their illness (Hubbard et al., 2010; Sinding and Wiernikowski, 2008). Some aims of papers were more specific in looking at particular aspects of adaption, such as sense of coherence (Thomé and Hallberg, 2004). Others focused on the use of qualitative methods to contribute to a more 'complete' patient perspective on the psychosocial impact of cancer (Sinding and Wiernikowski, 2008). Studies took different perspectives either from a clinical or psychological stance, but few studies looked at both perspectives together. This could be due to the lack of literature before 2008 when the gerontology-oncology concept was first recommended.

Some studies focused more on a particular stage of illness, such as at diagnosis or in the terminal stages (Hubbard et al., 2010; Hockley et al., 2005). The different emphasis on site-specific disease gives support for the need for further research to consider the meaning and importance of other cancers in different stages, particularly in the way professionals interact with patients and give psychosocial support.

From a methodological stance, some methods of generating data may have limited responses through the use of structured questionnaires (Thomé and Hallberg, 2004) or telephone interviews (Lewis et al., 1997). Small sample sizes of patients being interviewed with a certain diagnosis in qualitative studies may have limited the transferability of findings (Hubbard et al., 2010; Chouliara et al., 2004b). Conversely, some of the sample sizes were large (Harrison and Maguire, 1995) and may have lacked the richness in data which could have been generated from a smaller sample. Few studies had an ill-defined or lack of epistemological and ontological stance, which made the choice of methodology less substantive than they may have been (Bain and Campbell, 2000; Harrison and Maguire, 1995). There was limited in-depth exploration and analysis of patients' views (Bain and Campbell, 2000) or rigid inferences, as in the case of quantitative studies (Harrison and Maguire, 1995). Some studies had a large sample or had methodologies with outcome measures which did not allude to the interactive stance between professionals and patients, thus portraying a clinical stance to care rather than showing the social aspects of caring (Lewis et al., 1997; Puts et al., 2010; Thomé and Hallberg, 2004). Some studies obtained views from professionals rather than from patients (Lewis et al., 1997; Mohan et al., 2005).

Some studies considered the impact of care interventions in palliative care on professionals' care delivery (Hockley et al., 2005). Some studies looked at education relating to palliative care, but did not consider the focus of care in the care setting (Froggatt, 2004). Some studies related to the early stage of diagnosis and so were limited in their relevance to patients' needs throughout the trajectory (Hubbard et al., 2010). Some

studies were small in sample, which could have led to poor transferability (Chouliara et al., 2004b).

Studies which were of an evaluative or quantitative/mixed stance could be criticized for not considering a more qualitative approach which would have generated more meaning and perceptions, such as the use of a survey in Froggatt's study (2000b) or in the use of a questionnaire when considering attitudes (Kearney et al., 2000). It is argued that questionnaires lack the ability to assess professionals' perceptions of care, as the data collection tool does not consider the contextual nature of care delivery. Some studies which focused on older people's perceptions were not always obtained directly by patients, but rather through health care professionals' accounts (Mohan et al., 2005; Wood and Ward, 2000). Chouliara et al. (2004b) did not consider the professionals' perspectives, which would have contributed to the potential diversity of accounts between patients. This is of importance, considering that many older people are cared for in general hospitals and are seldom admitted to a cancer centre due to the lack of perceived need for referral, lack of attendance at screening, isolation and multimorbidities. Also, looking at the professionals' perspectives might have shown attributes which could be a result of working within a particular ward (whether non-cancer or cancer).

Summary of literature review

Key points from the literature review are:

- The geographical and ward context create a place and *interactive space* for older patients to be cared. From a macro stance, the location of the hospital suggests that

the place of care can result in inequalities of choice. The social construct of being older further augments this inequality.

- The wards have different specialties – some being medical, encompassing different patients with various illnesses while others are more specialist, housing patients with cancer. The context of the ward offers different expectations and supportive needs for patients depending on the focus of care and professionals within the wards.

- Professional perceptions are influenced by paternalistic and negative attitudes resulting in older patients with cancer having a lack of choice and options for care especially in the medical ward. While in the specialist ward there is more access for treatment and options for care. Attributes for interdisciplinary working are a means for effective collaboration enabling accurate assessment for patients who need appropriate treatment.

- Education has been shown to enhance the care delivery and competency of professionals, thus facilitating appropriate care for the person who is older, although studies have lacked the exploration of educational needs for the older patient with cancer.

- The chronological age of patients carries an underlying discourse which appears undeserving of appropriate care compared to younger people. This is reinforced due to the unique way older people convey their ability to cope. Older people tend to normalize their illness, believing they are not ‘deserving of care’. More specifically gender-related aspects further delineate their identity; men being more

stoical and drawing on inner resilience while women tend to look for external support.

Discussion of literature review and research questions

This section will provide a discussion synthesizing the scoping review into the two main themes: (1) hospitalization: the care environment (2) care delivery: psychosocial and professional needs. This discussion will provide a clear indication which underpins the support for this thesis and its theoretical and data generation methods.

The questions stated at the beginning of the review aimed to ascertain the following:

- What are the experiences of the older person with cancer in different care settings?
- What are professionals' perspectives of the older person with cancer in different care settings?
- What are the factors which influence care in different care settings?

Hospitalization: the care environment

Hospitals are the commonest place of death for over-65s, bringing into sharp focus the need for care which recognizes the unique needs of the older person with cancer (Gomes and Higginson, 2008; Green et al., 2008). Older people are commonly admitted to non-specialist ward settings with complex symptoms such as pain, fatigue and depression related to their diagnosis, as well as multimorbidity (Thomé et al., 2004a, 2004b; Balducci and Extermann, 2000; Goodwin et al., 1991; Goodwin et al., 1993; Puts, 2010).

The place of care delivery has been a significant Scottish priority over the past decades (NHS, 2010). Cancer care is predominately delivered in local general hospitals rather than cancer centres. For older patients with cancer, there has also been a shift in care from the hospital to the community (Scottish Executive, 2005; Scottish Government, 2008a, 2008b, 2008c; LTCAS, 2008). The lack of beds in specialist settings, the frequency of admissions to inappropriate wards, disadvantages older patients with cancer.

Despite the 'shifting balance' of care from the hospital to the community, complex cancer care delivery remains predominately in the hospital setting, especially for patients who are frail with multimorbidity (Seymour et al., 2011). This is a result of the inadequate management of symptoms at home due to lack of resources. Thus, older people tend to be hospitalized (Gomes and Higginson, 2008). Emergency admissions of older people accounted for the entire increase in bed days occupied by inpatients over the last twenty years (*National Framework for Service Change in the NHS in Scotland*, NHS Scotland, 2006). How the professionals care for the older person with cancer is a priority to ensure the provision of the most effective and appropriate supportive care which optimizes the patient experience (Puts et al., 2010).

Some studies have reported a lack of recognition of being older (Blank and Bellizzi, 2008; Harden et al., 2008). Studies relating to older people's personal perspectives with cancer state they have pertinent reasons for not wanting to be cared for at home. Many express a preference for being in hospital, as they are reassured by the presence of medical expertise (Chouliara et al., 2004b; Gott et al., 2004). Older people are commonly isolated at home dealing with the side effects of treatment, which may make them further marginalized from society (Wells and Kelly, 2008): thus, being in hospital can be seen as a

psychological and clinical supportive experience at times. Studies also state that older patients place great trust in health care professionals and feel comforted that their symptoms will be managed (Bungay and Cappello, 2009; Chouliara et al., 2004b). Also, being hospitalized results in patients feeling that they are less of a physical and emotional burden for their families (Bungay and Cappello, 2009; Giacalone et al., 2009).

Care delivery: psychosocial and professional needs

Over the past five years, geriatric oncology has been recognized as a specialty within oncology and geriatric medicine[21] (Blank and Bellizzi, 2008; Puts et al., 2010). Thus, the need to explore how older patients with cancer are being cared for is of paramount importance. Older people living with cancer experience inconsistencies in the way in which their clinical care is delivered by professionals, justifying further exploration of *how* and *why* patients are managed, bearing in mind clinical, social, personal and professional attributes. Considering particular clinical, social and psychosocial attributes for this group of patients gives further substantiation to the gero-oncology concept[22] as helpful to understanding the needs of this group.

Overall, growing old has an impact on patients' psycho-adaptation to cancer as well as their clinical manifestations. Studies within this section of the review demonstrate that the

[21] Geriatrics is a sub-specialty of medicine that focuses on health care of the elderly. It aims to promote health and to prevent and treat diseases and disabilities in older adults.

[22] The gero-oncology concept was recognized as a concept by Kagan (2008) and departs from the biomedical model of geriatric oncology. It embraces the cancer and ageing interface, which is interdisciplinary and comprehensive in scope (Bellury et al., 2011).

psychological and clinical impact of cancer for older people has a gerontological[23] and life-span perspective. The ageing processes impact on aspects of quality of life, with some people being alone and living with multimorbidity. Social circumstances can make a diagnosis of cancer less or more significant, depending on past clinical and social experiences. A holistic perspective recognizes an individual's discourse.

Thus, age is not only a chronological fact but is also seen as individualized. Variables such as gender impact on how patients convey feelings about their illness. The interlinking of the cancer diagnosis with past experience, gender and social ageing creates an interplay of factors which makes caring complex. Exploring how older people with cancer are perceived by others and perceive themselves portrays a picture of contradictions. The themes of being deserving or undeserving, having an inequity of service, normalizing their illness yet living with uncertainty, are challenges for the older person with cancer.

Professionals use assumptions which inform their delivery of care (Kearney el al., 2000; Kagan, 2008). Inappropriate tools are used to assess the older person with cancer, demonstrating a lack of appreciation of multimorbidity and the social impact of ageing (Hurria et al., 2006; Puts et al., 2010). Findings from a review of literature identified that the level of unmet needs in newly diagnosed older cancer patients after the start of treatment is high, and the most common needs are psychological and information needs. More research is needed which would focus on the needs of older adults with multimorbidity (Puts, 2010).

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[23] Gerontology is the social study of old age, the process of ageing and the particular social problems of old people.

In addition to a lack of assessment and unmet needs, professionals appear to endure hindrances such as a lack of time, which inhibits person-centredness, particularly in acute settings (Mohan et al., 2005; McCaughan and Parahoo, 2000). Professionals have emotional challenges when interacting with patients, with a lack of education being a major factor. This group of older patients are commonly treated in wards characterized by a lack of cancer care specialists or professionals who are experienced in care of the older person. There have been concerns that oncology professionals do not have the appropriate gerontology expertise.

There are two main issues that seem to hinder person-centred care[24]. The first issue is that professionals hold certain perceptions towards this group of patients, as has been discussed in several papers. This relates to the implicit societal perspectives of older people (Kagan, 2008; Kearney et al., 2000). Secondly, the place in which care is delivered appears at times to hinder the quality of care for this group of patients. Possible factors seem to be the inability to create an appropriate focus of care, due to a lack of resources within the clinical infrastructure (Mohan et al., 2005; Hockley et al., 2005). Nurses appear to have the most contact with patients in different settings providing supportive care, but find challenges in dealing with emotional care (Mohan et al., 2005): reasons for this appear to be partly that nurses who are not specialist have a lack of education in cancer and palliative care (Mohan et al., 2005; Hockley et al., 2005). In summary, factors of clinical and psychosocial care, place of care, education and experience all influence a person-centred process.

[24] Evidence has shown that being patient-centred requires the development of a therapeutic relationship between patient and professional. These relationships are based on trust, understanding and collective knowledge (McCormack, 2001, 2004; Nolan et al., 2004).

The above studies have looked at cancer and the older person from both clinical and psychosocial dimensions. There appeared to be underlying assumptions which both patients and professionals used to gauge the care delivery process. From this review, patients wanted the best care possible but also looked to their past lives to make sense of their illness, thus balancing up their options (past experiences) in relation to their expectations.

Consideration of the place of care is integral to understanding how older people manage their illness and support their families. However, lacking in some studies was the understanding of why and how professionals provide care to older patients with cancer in a hospital setting.

Having reviewed the findings of the above scoping review, the current study will provide insight into the identified gaps in the research through obtaining perspectives of care in two wards within a general hospital. This is for four reasons: (1) there are gaps in British and international research which consider the therapeutic interaction between patients and professionals; (2) supportive care is complex due to their existing diagnosis and multimorbidity, therefore patients are needing care which encompasses the ageing process, life context as well as their existing illness; (3) having insight into different care settings and the significance of interaction with others, older patients with cancer may identify aspects of care which are of benefit when being hospitalized; and (4) studies do not always explore how the psycho-adaptive responses relate to being older and living with cancer in

a 'life mostly lived'[25]. Exploring this discourse while in hospital may reveal how older people have particular coping mechanisms, including how they make sense of their illness. This study will explore the psychosocial and clinical approaches to care, generating data from older people with cancer and professionals involved in their care delivery.

Aim of the study

- To determine whether a medical or specialist care setting is the most appropriate context for the delivery of person-centred care[26] with the goal of providing social and emotional support to the older person with cancer.

Research questions

How do these two settings (medical ward and specialist ward) shape:

- Older patients' and professionals' views on diagnosis and care delivery?
- Professional roles and responses to care delivery?
- The psychosocial experiences of older patients?
- Interpersonal dealings between patients and professionals?

The next chapter will discuss the theoretical underpinnings, research design, data generation methods and analysis. Ethical issues within the study are also addressed, including the importance of reflexivity as a researcher.

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[25] 'Integrating cancer into a life mostly lived' is a theme from Kagan's (1997) research which captures the interconnection of advancing age, understanding one's self and experiencing cancer.

[26] 'Person-centredness' is a term that is becoming increasingly familiar within health and social care at a global level; it is being used to describe a standard of care that ensures the patient/client is at the centre of care delivery. In this thesis the concept relates to the work developed by McCormack and McCance (2010).

CHAPTER THREE

Methodology

Introduction

The previous chapter provided an overview of the literature, particularly in relation to locality, specialist and non-specialist settings, professional perspectives, roles and education. Patient attributes relating to psychosocial, young and old, older people with specific cancers and the ways in which they cope were discussed. The review demonstrated that there was a lack of research which considers professionals' *and* patients' accounts regarding both specialist and non-specialist settings. The current study explores the shared sense of meaning found between patients and professionals within organizational contexts in which interactional processes occur.

This chapter will be presented in two stages. Firstly, a pragmatic rationale for the study design and methods will be given. Secondly, findings from sampling and the process of analysis will then be discussed. The positioning of the researcher and reflexivity will also be considered.

Philosophical framework

The theoretical underpinnings of research address the philosophical stance that lies beneath the methodology. In doing so, assumptions about the human world and social life are also addressed. The next two sections will seek to address the ontological and

epistemological basis of the study. The ontological basis of this study is described as *what* constitutes the social world and how we can go about studying it (Mason, 2005). The epistemological basis is described as *how* we come to know the social world (Polit and Beck, 2012). It is important to have these theoretical perspectives in a research study to allow broad organizational and interactional stances to be augmented to form the 'intellectual puzzle'[27] of the research question (Mason, 2002).

Ontology

Crotty (1998) defines knowledge that is constructed through the world and objects within the world. The ontological basis of this study supports the distinction that there are multiple perspectives of reality. Thus, it allows the researcher to be a 'sceptical stranger', questioning the notions of ageism and living with cancer. Both notions have different meanings to different people, one being seen as less important than the other. This hierarchy of perceptions is displayed through interaction.

An ontological perspective can be a difficult concept to grasp, as one may never have appreciated the essence of social domains prior to learning about the perspective (Crotty, 1998). However, once it is acknowledged, the researcher can begin to see her own view. While the ontological stance is important, it is equally important to define how the research is expressed.

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[27] Intellectual puzzles can take a variety of forms connected to the ontological and epistemological positions that are encapsulated in the research and grounded within the specific context of the research problem (Mason, 2002, p. 18).

Epistemology

Epistemology is the 'theory of knowledge embedded in the theoretical perspective' (Crotty, 1998). It focuses on making sense of the world through knowing how we know what we know. Berger and Luckmann (1966) convey the notion that how someone addresses their reality is dependent on the context in which they live. They use the term 'reality-oriented approach' to crystallize the seminal aspects of social constructionism. This approach assumes that knowledge is gained through our realities, which are multiple (Burr, 2003).

Social constructionism

The ontological basis of the theory underpinning this study is social construction. Social construction was chosen because it allows the researcher to not only look at subjective meaning, but to also explore the processes of constructing social situations (Sarantakos, 2005). Everyday structures that guide and explain views and opinions are explored. Rather than there being one truth, reality is being continually constructed over time through the process of interaction; it is shared by many. The research participants are viewed as central to the social construction of reality and developing an understanding of what it means to the older person with cancer.

My reasons for choosing a social construction and constructionism-based approach are based on the following factors:

- Social construction was chosen as an approach rather than other paradigms such as phenomenology because it acknowledges the truth or meaning which emerges from different engagements with multiple realities of the world.

- The true essence of this study is situated in the relationship between older patients with a diagnosis of cancer and the multiple realities (social, clinical, emotional, physical, person-related and/or cancer-related). These multiple realities display to professionals and other patients during their hospitalization. In addition, this approach is congruous to this study, as it focuses on the context of people's everyday lives in order to understand perceptions.
- Social constructionism is highly apt for a qualitative study. It provides a coherent theory to substantiate data generation methods which focus on understanding the social issues that occur as a relational stance between people.
- Social constructionism focuses on how various practices play out in relationships within a particular organization, addressing language and the particular nuances.

Social constructionism consistently seeks to take a social critical stance towards our understanding of the world in a deeper way than is described by social construction. It questions taking for granted assumptions in the *categorization* and *labelling* of terms (Burr, 2003).

Application of concept

An example of a concept within this study is older people. The categorization is based on whether they are being defined as deserving or undeserving. For example, the probability of dying of old age may mean that an older patient is not perceived as being in need of palliative care. Similarly, an older patient who is self-managing their illness may not be perceived as being the norm. Social constructionism questions why categories claiming older people as 'undeserving' or 'deserving' are helpful or unhelpful in the portrayal of old age (Burr, 2003).

Another possible label relates to the different perceptions of people having a certain cancer versus having another illness (for example, breast versus lung cancer). It is of interest to question why cancer care and geriatric medicine are not always perceived equally when making clinical decisions (Puts et al., 2010). Another categorization is the ward setting; to question why care is defined by a medical model rather than the social construction of illness. Historically, care tended to be based on the medical model, which can be seen as unacceptably narrow, as in reality illness cannot be reduced to a biomedical process (Bury, 1982; Williams, 2000).

Through using social constructionism using different lenses, such as social, clinical, professional, personal, cancer, older, person and patient, data are crystallized. Berger and Luckmann (1966) see social reality as a range of processes and practices, which suggests that there are multiple realities of knowledge. Berger and Luckmann (1966) also state their contention that the sociology of knowledge must concern itself with whatever passes for ‘knowledge’, both in a society and individually (Berger and Luckmann, 1966, p. 15).

When focusing on the different elements of social constructionism, it is important to look at two main stances that can be applied to all the elements. There are two forms of social constructionism. The first focuses on *culturally available discourses* (Burr, 2003), and the second focuses on *personal identities*. Thus, the theory of social constructionism can be categorized as having both a macro and micro stance. It is important to further define these terms.

The macro and micro stance of social constructionism

Berger and Luckmann (1966) argue that the social world is constructed and becomes a reality through human action and interaction. While Burr (2003) discusses different perspectives on the social constructionist approach, she also argues that the two perspectives of macro and micro should not be seen as mutually exclusive, but rather as a spectrum.

At a macro level, applied to this study, social constructionism demonstrates how older people came to be seen as a problem group due to three interrelated factors: poverty, restricted employment and marginalization; physical deterioration; and demand on resources (Thane, 2000; Victor, 2005). This study is based on the sociological proposition that old age is perceived as synonymous with ill health, which results in a lack of acknowledgement of older people as individuals and the subsequent perception that they are a homogenous group.

Drawing on social constructionism, the ward can be viewed as a society made up of norms, rites and rituals (routines, ward rounds, report giving). This ensures that roles are internalized through linguistics and knowledge to achieve a cohesive workforce. Berger and Luckmann (1966) discuss how roles are institutional representations. Each role has a socially-defined appendage of knowledge and ‘moral rhetoric’ which is evident in ward environments. Social life is played out in the roles we acquire and invent or are forced into (Gergen, 1999; Goffman, 1959).

Hospital settings make their strategy and policies using a body of knowledge that produces certain socialized behaviours. Macro social constructionism is helpful in explaining how

societal and institutional discourse influences role behaviour. Cultural and organizational discourse is also created and reinforced through ongoing interaction. This interaction is defined through micro social constructionism.

Personal identities

Micro social constructionism focuses on the everyday discourse between people and involves multiple realities rather than one 'truth'. Shotter (1995) claims that when people interact it is 'like a dance', where people are responding to each other's rhythm and posture, thus focusing on the joint effort of a dialogue (Shotter, 1993). Thus, only a small part of the totality of experiences is retained in consciousness, but reality and culture trigger certain experiences that are shared through the power of words. Professionals assert that symbolic rites and rituals reinforce socialization, as do the roles which people adopt. These roles are described as actors in the social context (Berger and Luckmann, 1966). Ward settings are like 'platforms' in which professionals enact their expected roles. While patients also perform the role which can be perceived as more subservient; being older and ill makes them feel more vulnerable especially in a ward environment. This is reinforced by the implicit paternalism which is inherent in how professionals display values and beliefs held towards patients. Knowledge is gained in the form of norms, values and emotions. These roles are objectified linguistically, through internalization of these roles and knowledge (Berger and Luckmann, 1966).

Language is a cultural resource as well as a socially-oriented practice (Wetherell, 2001; Potter, 1996). General discourses are significant, such as gender aspects within the family. Mason (2002) illustrates how discourse provides an interpretive framework for

constructing social reality within a context with particular kinds of people. While the discourse between people is a shared vision, it is also important to consider that social construction shapes the concept of the self.

Study design

Rationale for choosing a qualitative approach

The epistemological and ontological position and the grounding in social constructionism influenced the research questions. Other influences included the literature review, the nature of the research questions and practical considerations of how the research aim and questions could be explored by the researcher. Polit and Beck (2012) describe the qualitative researcher as one who provides a rich and holistic description of data which is nested in a real context. The 'lens' of the researcher is to gain a holistic (systemic, encompassing, integrated) overview of the context under study, including the explicit and implicit messages which are generated from the data (Mason, 2002; Polit and Beck, 2010).

The data recreate a slice of interactional experience and give the researcher insight into the situation. Qualitative research is relational, connecting biography to the lived experience. It is contextual and interactional; it captures the meanings that are present in a sequence of experiences and it attempts to unravel the multiple meanings that occur within any interactional experience (Denzin, 1989, p. 102). Qualitative research enables the researcher to explore complex and sensitive issues, such as feelings relating to cancer and the older person, through an explorative account of multiple perspectives and experience (Barbour, 2008). The following section considers the choice of methods in generating data.

Choice of methods

The methods chosen to generate this knowledge were pilot focus groups, semi-structured interviews and dissemination focus groups. Three methods of data collection were used in this study; pilot focus groups, semi-structured interviews and dissemination focus groups. There were five stages to the data generation, as illustrated in Figure 1 below. Firstly, issues from the gaps in the literature review and my previous roles formed the prompts for the two pilot focus groups (professionals[28] only). Secondly, one focus group was carried out with professionals in each of the wards. The purpose of the focus groups was to identify themes to explore in interviews for professionals and patients[29]. Thirdly, a pilot for professional and patient interviews was carried out on each of the wards. This allowed further refinement and development of the semi-structured interview schedules for patients and professionals. Fourthly, 20 semi-structured interviews informed the agenda for the three dissemination focus groups[30, 31] (see Appendix D).

Fifthly, the three dissemination focus groups further informed ongoing data analysis. All these stages were not considered in isolation, but seen as an iterative process.

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[28] The term 'professional'. In order to understand the concept of professionalism it is important to define it. It has been defined as a "chosen, paid occupation requiring prolonged training and formal qualification". McCormack and McCance (2010, p.97).

Professionals, therefore can be defined as individuals are expected to display competent and skilful behaviours in alignment with their profession.

Although this study has included other professionals the main purpose is to explore the care delivery that nurses give to older people with cancer in two ward settings. Including other professionals allowed comparison to others.

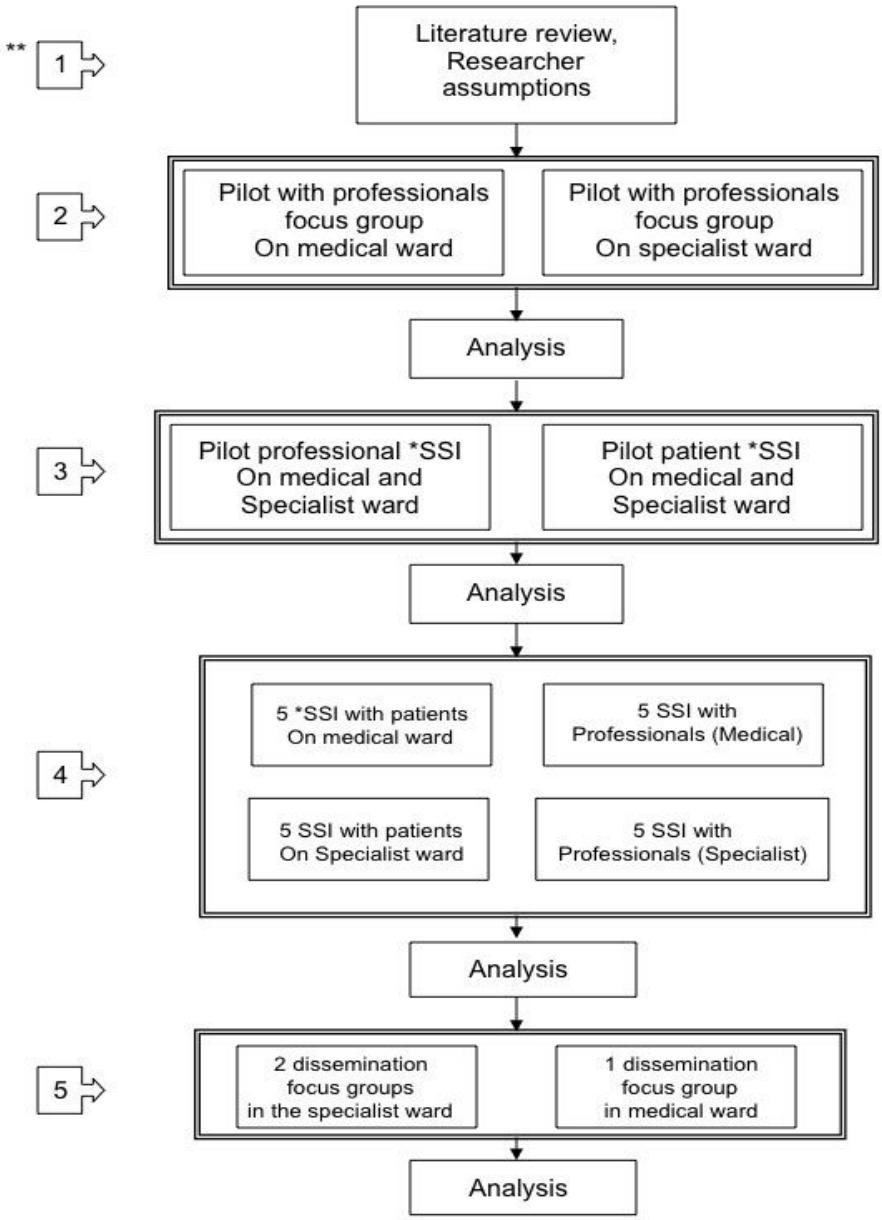
[29] The ethics approval committee would not allow focus groups to be carried out with patients.

[30] Dissemination focus groups were a means of clarifying and affirming earlier findings.

[31] It was not appropriate to seek perspectives from family members as this did not fit with the focus of the research; aim and questions.

The interview schedules are to be developed from the focus group interviews and the literature review. The schedules were also discussed with the supervisory team. The interview schedules involve a series of headings and questions were open-ended so as to allow participants to elaborate. Prompts also help to ensure questions that were asked which may not have come from the participant.

Figure 1: The five stages involved in the data generation



* SSI = semi structured interview

** = arrow shape denotes stages

Pilot focus groups

Pilot focus groups were selected for generating data which would:

- Explore group qualities and opinions on how this affects the care, e.g. role, clinical opinions, focus of care.
- Identify particular education and experiences that enhance or conflict with care or psychosocial support for patients, e.g. cancer care education.
- Understand how people perceive the care of the older patient, e.g. from role perspectives, setting, referrals.
- Explore issues which participants may not discuss in an interview, e.g. emotion management, how to manage moral and ethical issues in stopping treatment.
- To identify themes for interviews for both patients[32] and professionals.

A focus group is defined as 'any group discussion where the researcher is actively encouraging of and attentive to the group interaction' (Kitzinger and Barbour, 1999, p. 20). Focus groups are helpful forums in guiding group discussions through different topics. They also allow the researcher to ascertain people's reasoning in certain events. Focus groups are beneficial when respondents might find face-to-face interviewing intimidating (Mason, 2002; Krueger, 1998). Focus groups encourage participants to focus on each other rather than the researcher, who rather than controlling the discussion, fills the role of facilitator (Bloor et al., 2001), encouraging interaction between participants – exchange of ideas, asking questions of each other and commenting on others' experiences. Wilkinson (1998) refers to this as the 'co-construction of meaning'. It has also been stated

[32] The ethics panel did not allow the researcher to carry out focus groups on patients.

that focus groups can provide a forum for mutual support (Krueger, 1998). The dual nature of focus groups being synergistic in generating group opinions and mutuality between professionals is obviously favourable.

Semi-structured interviews

Semi-structured interviews were selected for eliciting data from health care professionals in order to:

- Explore individual qualities and opinions and evaluate how this affects the care, e.g. role, clinical opinions, focus of care.
- Identify particular education and experiences that enhance or conflict with care or psychosocial support for patients, e.g. cancer care education.
- Understand how individuals perceive the care of the older patient, e.g. setting, referrals.
- Explore issues which participants may not discuss in a focus group setting, e.g. emotion management.
- Further probe themes highlighted in the focus group.

Semi-structured interviews were selected to elicit data from patients in order to:

- Explore individual views and opinions regarding their care, e.g. treatment choice, their age, whether care was supportive or active.
- Discover what they want from their experience of care, what helped or what inhibited their care needs, e.g. power issues, paternalism, therapeutic relationships.
- Search for individual qualities and opinions and assess how this affects the care, e.g. individual care issues, stage of disease.

- Explore patients' biography and how this informs the research about how patients deal with their illness.

The aims for the interviews with professionals and patients are different and include professional, personal, social and clinical dimensions. Semi-structured interviews involve one-to-one interactions between two people (Mason, 2002). Semi-structured interviews were chosen because of the focus on the constitution of knowledge and the discursive constructions of the social and the self (Wetherell, 2001). Interviews also allow interaction to occur, which was significant due to the sensitive issues being discussed (Kvale, 2007). Interviews allow more privacy than may have been afforded in a group interview, such as in focus groups. Rapley (2001) argues that interviews are performances, involving a two-way encounter, and that it is essential that the researcher owns the questions.

Semi-structured interviews may give health care professionals a forum to talk about more sensitive issues, such as personal attitudes towards the older patient or inter-professional conflict. Older patients also tend to find it difficult to disclose their thoughts, due to the belief that they have little influence over their care (Kearney et al., 2003).

Patients may feel that if they speak of bad experiences this may affect their care (Entwistle et al., 2012; Chouliara et al., 2004a). Focus groups may have reduced this perception (Bloor et al., 2001). To reduce anxiety, participants were assured of confidentiality, being informed of the purpose of the letter of consent and the nature of the study. To reduce coercion of participants, it was important not to lead discussion, but rather to try to understand and get into the other person's shoes (Mason, 2002). Looking for non-verbal communication, such as tone or gesturing, was central to identifying what was not being

said, or the use of sarcasm or wit as a way to cover true meanings (Wiles et al., 2007). To ensure that the free flow of conversation will be systematic, Barbour (2008) advises researchers to tick off questions as they are being asked, so that there is a strategic process.

Dissemination focus groups

Barbour (2005, 2008) states that in contrast to other qualitative methods, focus groups afford the unrivalled potential to engage in 'second stage sampling'[33]. The reasons for carrying out dissemination focus groups[34]:

- To enhance analytical sophistication as other members contributed to the data.
- To enable respondent validation to enhance authenticity.
- To generate further data to ensure rigour in the 'crystallization'[35] of findings.

For the dissemination focus groups, quotes from the focus groups and interviews will be used as 'stimulus material' in order to determine to what extent perspectives were shared and to focus discussion.

There were more professional roles in the dissemination focus groups, so the findings were further enriched by more 'diverse voices' from different professionals. Because there were more visiting professionals, there was less of a homogenous feeling of being from the same ward. Due to the heterogeneous nature of the three dissemination groups there

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[33] Second stage sampling is also called 'wildcard' groups (Kitzinger and Barbour, 1999).

[34] The term 'dissemination focus groups' was used as new members were included from the first-stage focus groups.

[35] Richardson (1991) suggests that it is more helpful to conceive complementary rather than competing perspectives, and offers the term 'crystallization' as an alternative to triangulation, which allows these differing perspectives to be viewed.

was more of a reflective discussion perceiving different roles as having certain challenges. There was also more of a comparison of the two wards as most of the members of all three dissemination groups were visiting members. It was intended that a second dissemination focus group could be undertaken in the medical ward, but due to a virus the ward was temporarily closed. The next section will address the reasons for combining methods in generating qualitative data.

Combined methods

The combined methods relate to data generation of pilot focus groups and semi-structured interviews. Both methods adopt the active role of the researcher as integral to the generation of data. Both allow for a flexible questioning route and analysis of vast amounts of data, using an iterative stance of refining themes, categories and codes.

However, there are a number of differences between focus groups and in-depth interviews. Both are essentially forms of interviewing, but the approach is different. Choosing pilot focus groups first enabled a dynamic approach which was open to the further refinement of questioning. This allowed a greater scope for questioning, which might have been more restricted if a semi-structured interview had been used first, as that type of interview may have a limited diversity of accounts due to being conducted with one person at a time (Seale, 2004).

During the focus group or dissemination focus group, not giving the focus of control to the researcher will enable a diversity of discussion, which might not have been gained through a one-to-one interview (Fern, 1982). Focus groups have a better potential to explore how accounts are articulated, censored, opposed and changed through social interaction; how

people prioritize; and what language they use (Puchta and Potter, 2004). They can also be less predictable than interviews in terms of how the discussion is likely to progress (Barbour, 2008). Rapley (2001) stresses that it is important not to see one method of data generation as being better than the other, and stresses that mixing methods allows for multiple perspectives to be accessed in order to develop a fuller account of the phenomenon under study[36].

Appendix D gives full descriptions of the questioning routes for the semi-structured interviews, focus groups and dissemination focus groups.

Appendix E provides further discussion of the questioning routes for the semi-structured interviews, focus groups and dissemination focus groups. Particular skills used in the focus groups and semi-structured interviews are highlighted in Appendix F.

Purposive sampling

According to Polit and Beck (2010), purposive sampling is a non-probability sampling method in which the researcher selects participants based on their personal judgment about who will be most informative. The objective is to reflect diversity, and to provide in-depth information (Mason, 2002). Sampling was guided by the literature review, as well as the ontological and epistemological underpinnings of the study. It was difficult to predetermine the size of the sample or the categories of patients or professionals that would be generated. Mason (2002) states that sample sizes need to be large enough to

[36] However, due to ethical conditions for this study it was only permissible to carry out mixed methods for professionals.

include participants with varying attributes to allow for an optimum comparative sample. Samples also have to be controlled to ensure the data set remains manageable enough for comprehensive analysis.

Sampling criteria and sampling grids

Barbour (2008) defines sampling grids as a scheme for ensuring adequate coverage/diversity in selecting participants. The grids list combinations of characteristics likely to have an impact on perspectives and experiences.

A sampling grid of patients was created that included age, gender, ward, stage of illness, treatment intent (chemotherapy, radiotherapy or both), supportive care and disease type. The sampling grid for professionals included past losses, past clinical experiences and qualifications.

Barbour (2008) and Mason (2002) recommended that the sampling grid not be seen as static, but as a tool to help in progressing preliminary analysis, with the potential to augment the sample as new, potentially important characteristics emerge. It was useful to look at data which considered patients of different genders and how they managed their illness. Barbour (2008) and Mason (2002) alert us to the need for creativity rather than luck in generating comparative data.

Challenges in sampling patients

Potentially eligible patients were identified by health care staff and their eligibility was judged by the researcher on the basis of both staff's and researcher's clinical judgement. A number of patients were non-eligible for enrolment for a number of reasons such as not

yet diagnosed or had just been admitted. Some patients did not get to the interview stage (due to physical frailty or being ill on the day) and one had practical difficulties (e.g. patient was taken for tests or treatment). Some patients were not recruited due to paternalistic attitudes from professionals:

> *Some patients were perceived as being too old to be interviewed or too frail. This highlighted the complexity and intersection of being old with co-morbidities (field notes February 2008).*
>
> *On reflection, the patient sample, despite professionals being paternalistic at times, except one, were in the palliative care stages. The sample of patients being mostly in the palliative care stages with some being newly diagnosed was a significant finding (field notes March 2009).*

This is seen in other studies where the complexities of being older and having cancer made them more vulnerable and unable to be interviewed (Chouliara et al., 2004a). It is worth noting that the recruitment data presented include only patients that come to our knowledge after identification by staff and so they are specific to the scope of the study and, although indicative, do not constitute the population of older patients with cancer coming through hospital care.

Furthermore, health care staff acting as ‘gatekeepers’ in the early stages of patient identification may increase the risk of selection bias in this study. Although identification is guided by the study’s inclusion criteria, it may have been compromised. Previous research has shown that potential participants may not be asked due to paternalistic assumptions towards older patients in health care (Walker et al., 1998; Ferrell, 1999; Kearney et al., 2000).

Challenges in sampling professionals

Participant recruitment can be particularly challenging when the intended study participants are health care providers within a ward setting as opposed to patients. Discussions of the challenges and successful strategies associated with provider recruitment are limited, particularly regarding professionals in two ward settings. Professionals maybe chosen for their favourable responses and loyalty to the ward over the years. However, Mason (2002) stated to acknowledge the interaction between participants and researcher is essential to reduce bias. In sum, recruitment for this study had unique challenges relating to societal perceptions of paternalistic attitudes to the older person which may result in misrepresentation. Respondents also, being in a hospital environment, add to their physical and emotional vulnerability. Professionals may also encounter feelings of 'not talking out of school' while wanting to be morally correct in discussing factors which affect clinical practice and the safety of patients.

Methodological challenges: older hospitalized people with cancer

As identified in the literature review, older people with cancer often face the prospect of cognitive and physical frailty, increased vulnerability of psychological distress and limited access to resources (Chouliara et al., 2004a; Repetto et al., 2003). Older people's experiences differ significantly regarding medical and psychosocial problems. This also extends to the health care and treatment they actually receive, compared with those of younger patients (Walker et al., 1998; Ferrell, 1999; Kearney et al., 2000). Maintaining self-care as well as improving treatment and care delivery of this group of patients requires an understanding of the multiple medical and psychosocial issues encountered in

such patients. Furthermore, although the challenges involved in conducting research on patient experiences in cancer (Entwistle et al., 2002), especially palliative care (Addington-Hall, 2002), there is a lack of literature addressing the specific challenges of investigating the experiences of older people with cancer (Chouliara et al., 2004a).

These factors present ethical and methodological challenges for conducting research in such patients, especially interviews in acute care settings (Maly, 2000). From a physical perspective, being older and living with cancer may impact on the ability to give valid consent and participate in research. Certain factors which impact on interviewing older patients with cancer have been identified as: high levels of fatigue and other distressing symptoms, high levels of cognitive impairment, limited functional status, increased physical frailty and chronic pain, high levels of comorbidity and polypharmacy. There was also evidence of speech difficulties, psychological distress, worries regarding their long-term care (Addington-Hall, 2002).

It has been suggested that because of the above difficulties, older patients with cancer may be particularly vulnerable (Chouliara et al., 2004a; Hey, 1999). In addition, there might be only limited possibility for such patients to benefit from research and subsequent developments in the long-term.

Chouliara et al. (2004a) argues that these factors may interfere with three principles of ethical research: first, valid consent to participation; second, the principle of ‘benefit from participation’ and ‘do positive good’; and third, the principle of ‘do no harm’. In particular, cognitive impairment, leading to impaired decision-making capacity, may interfere with the concept of patient autonomy, as well as the ability for voluntary,

informed and competent consent, the three vital conditions for valid consent (Harris and Dyson, 2001). In addition, the ability to consent to and complete an interview can be affected by vision and hearing problems (Gregson et al., 1997). In sum, due to the vulnerability of older people with cancer, the researcher needs to balance the need to generate data while also upholding the ethical principles.

Study approach

Study setting

Previous research has identified that the place of clinical care is a major influence on patient experience, and this merits further exploration. The study was carried out in a general hospital situated in Fife, on the east coast of Scotland, consisting of some small urban communities, but mostly of rural populated areas. Fife has a high population of older people. Statistics were reviewed from the Fife Health Board to identify what wards would best capture the older person with a diagnosis of cancer. The two wards chosen were the most highly populated, but also had different specialties and focus of care, which added a diversity of accounts.

The population of Fife was compared to other ICS statistics in Scotland. The area selected for this study is similar in incidence to other regions (Scottish Public Health Observatory, 2014). Appendix M gives examples of the incidence of cancers within the wards chosen for the study. Fife is classified as a rural area[37] (Scottish Government, 2012).

[37] There are pockets of 'remote rural' to the east of Newburgh and west of Falkland.

Two wards were chosen, one medical and the other specialist[38]. The medical ward and the specialist ward were chosen following a review of inpatient statistics of admission to wards at the hospital. Using both patient and professional data allowed for the comparison of both professional and personal perspectives on the data. The organization was the 'general hospital'. The selection of two wards gave further diversity in perspectives of the philosophy and focus of care. Principal care for older people with cancer is provided in the Hospital A and B in the region of Fife. Hospital B was chosen as it had the largest inpatient admissions of older people with cancer. A medical and specialist ward was chosen, as this also had the highest admission of older people with cancer compared to other wards.

Recruitment

The process of ensuring the study had ethical approval was to proceed through the Fife and Forth Valley Research Ethics Committee (see Appendix I). They made some recommendations in relation to the recruitment and selection of patients:

a) I will allow patients adequate time (perhaps a day or two) to settle in after admission to the ward, at which time they are likely to be at their most vulnerable. I will enlist the help of the medical and nursing staff in determining which patients might be most appropriate and who should not be approached.

b) I accept the medical or nursing staff member's interpretation of terminal illness in the context of the research and will not include patients at this stage.

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[38] The medical ward is known as ward A. The specialist ward is known as ward B.

c) I will not approach patients directly. The nurse or doctor will introduce the research to them and provide them with copies of the information sheet. Only then will I approach and recruit them.

Wiles et al. (2007) alert us to the fact that gatekeepers can withhold people who may otherwise be willing to take part in the study. Those identified as being potentially suitable participants were given an information sheet about the study and a phone number where they could call me. All efforts were made to ensure that gatekeepers facilitated access to a wide range of participants (Mason, 2002).

At the planning stage of the study, it was decided to invite professionals who visited both the wards, so that they could add data from perspectives on both the wards. The charge nurses/senior nurses were the gatekeepers to recruitment and access to professionals and patient participants. These caused practical challenges in purposive sampling as noted in the field note:

> *Some professionals who wanted to be interviewed could not, due to staff resources at the time. This aspect impacted on the type of data generated (field note January 2009).*

At the beginning of every week it was important to visit the ward and ask what patients had been admitted over the weekend and if there were any expected routine admissions. When there was a potential patient who may be suitable it was important to ensure they had been in the ward for at least 48 hours. Then an appropriate time was arranged to speak to the patient once the patient had consented. Staff recruitment was also planned on the subsequent Monday once professionals had consented to being interviewed. See Appendix N which displays a time line.

Once professionals consented to the semi-structured interviews or pilot focus group they often came to the dissemination focus group. Two of the professionals self-referred after hearing about the study at a senior management meeting. MacDougall and Fudge (2001) discuss the importance of acknowledging non-participants in the study. It was noted that within the sampling frame there were no doctors. One doctor was going to be interviewed, but was then too busy to make the time. This formed a field note in itself considering who came forward to be interviewed and who did not. The issue of gatekeeping reinforced the process of ongoing reflection of who is needed to undertake the research and who was actually interviewed. Recruitment was governed by the people in the wards with different cancers and ages. Professional sampling was governed by the occupation and ward base.

Ethical issues: data generation and analysis

Ethical issues in data collection require the researcher to continually reflect on the informed consent of participants purposely throughout the research process. Mason (2002) sets out six questions which were asked throughout the data generation process. These are:

- Have I honoured my commitments about confidentiality and privacy?
- Have I acted in the spirit of the informed consent which I received?
- Have I fulfilled my responsibility to produce good quality research?
- Have I used my research and my explanations effectively and morally?
- Have I generalized appropriately?
- Do I have responsibility to anticipate how others might use my research and explanations?

- In general, am I clear about both my rights and my responsibilities, in respect of my data, my analysis and my explanations?

Confidentiality

The only other people who had access to the transcripts were my Ph.D. supervisors, who were unaware of the patients' identities. Barbour (2008) states that confidentiality goes far beyond ensuring tapes are hidden under lock and key and that it is more of an ongoing imperative as dissemination occurs.

Beneficence and non-maleficence

It could be argued that, given the research process, having an agenda and prompts to encourage a line of questioning may create a tension between being a researcher and also being mindful of what impact the questioning would have on the participants (Seale, 2004).

The very setting of the study being on ward areas gave professionals an institutional power, and so patients may have felt disadvantaged from the standpoint of being a patient. A way of reducing this was highlighted in the patient information letter, indicating that their accounts would be anonymous and would only be known to me. In support of being interviewed, some patients commented that the process would improve the care of others.

There was resilience from some patients, as they had no other choice but to 'fight it' and 'get on with it'. This discourse could have been a way of blocking further questioning by drawing on cultural attitudes of the 'fighting spirit', which was typical of their generation. As Foote and Frank (1999) and Corner (1993a, b) suggest, drawing attention to dominant

discourse may be a way of easing some of the vulnerability that is produced when personal situations of loss are set against cultural prescriptions. It was important to acknowledge the therapeutic role of the researcher in enabling patients to reflect on their life goals.

Throughout participant interviews, some patients recounted their fears of feeling unsafe or unable to go out due to their symptoms or lack of help. It was also felt that speaking with some patients might make them feel comforted, as talking with me and having company. I reflected on how patients might feel after the interview was complete, further confirming their loneliness. Hey (1999, p. 107) notes that ending interview contact 'may well mean consigning older people back to a heightened awareness of social isolation'. I was very aware throughout the interview of overwhelming patients. In contrast, Hey (1999, p. 107) expresses concern that loneliness may propel elderly people 'to disclose information in order to retain the company of the researcher'.

Coffey (1999) and Beauchamp and Childress (2001) state that tensions in qualitative studies are often held in the personal diaries of fieldwork. Mason (2005) also discusses that how we reflect is important to recognize the epistemological stance. I reflected multi-vocally (Mason, 2005), seeking to show a range of interpretations and voices in the data and willingness to critique my own interpretation as well as that of others.

Coercion

The charge nurses of each of the wards were the gatekeepers to the research. Wiles et al. (2007) remind us, however, that gatekeepers can deny access to some willing participants. It was questioned, although charge nurses were the gatekeepers, to what extent they felt

that they had to participate. This has also been mentioned by Mason (2002), who reinforces that, although consent is given, it may not be true consent. From a formal written perspective, letters regarding the research were given out to potential participants (see Appendix J). The letter outlined the research topic, but I would also always discuss the type of questions I would be asking before the interview started, just in case the participants wanted to change their minds.

Data management and analysis

Data management is essential to understanding the data. The theoretical underpinning of the thesis appealed to interaction between people, managing multiple truths and different sources of meaning. To accurately reflect this, all interview transcripts were recorded with a digital voice recorder. Voice files were then transferred into a computer which was password-protected. Data were categorized into electronic files. Within these files were 'patient' files and 'professional' files. The professional file had three further sub-files relating to the pilot focus groups, interviews and dissemination focus groups.

The organizational system was consistent throughout the data sets. Mason (2002) warns that although ordering data is banal, it is the start of the researcher making sense of the data. Thus, it is important to be clear in what constitutes data. The data in this current study are referred to as the transcripts, field notes and supervisory notes generated through interviews. Organizing the data was an important step in indexing and categorizing the data. This will be discussed in the process of data analysis section below.

The process of data analysis

The role of the researcher is to gain a 'holistic' overview of the context, looking for explicit and implicit messages. Qualitative research allows the researcher to attend to categories and priorities within the text. Mason (2002) encourages the researcher to be pragmatic about analysis through looking at the questions of 'What is going on here?', 'What are the key factors?' and 'How can I make sense of this?'

It is also of utmost importance to demonstrate to others how the analysis was systematic and rigorous, showing a clear progression of thought. The diversity of purposive sampling had potential for further comparisons, and diversity in sampling grids was used to enable further analysis.

Analysis was seen as dynamic and open to change, as theory and explanations developed. A systematic rigorous approach was guided by analytic induction and theoretical sensitivity. Ritchie and Spencer's (1994) framework was used as this places emphasis on using explanations and exceptions to an analytical advantage. The five stages are: familiarization of the themes within the data, identifying a thematic framework, indexing, charting, mapping and interpretation. Framework involved:

- Code data into categories so that items with shared characteristics are placed together.
- Integrate categories and their properties.
- Reach theoretical saturation.
- Write a theory and revise as ongoing analysis occurs (Seale, 2004, p. 242).

Purposeful sampling strategy and the sampling grids enabled me to develop new codes through explanation building as I moved back and forth within the data. Purposeful sampling also allowed me to:

- Collect data from different persons/situations, thus building on the truths that were being developed. The various major themes such as personal/professional, clinical/social, societal/individual allowed me to see links between themes, categories and codes.
- To recognize knowledge prior to analysis, and that there were assumptions about the findings based on my past roles. Negative cases could be identified and provide a more in-depth analysis of experiences of hospitalization.
- 'Framework' allowed me to see the links between categories from different stances. The theory generation promoted reflection on presuppositions from the literature review and to crystallize particular nuances of this study, which makes this study unique or developed differently to others.
- The strength of 'Framework' was that it enabled me to think creatively to determine meaning, salience and connections between the data.
- Analytical grids allowed further systematic rigour within and across themes.

The focus group data were considered first, but then as the data from the patient and professional interviews came in simultaneously, it was necessary to compare and contrast the four data sets at once. Integrating all data sets was helpful, enabling the examination of themes within and across the data sets. It was fruitful to process two transcripts from patients (different wards) with professionals (different wards), which facilitated the

process of 'indexing' and 'charting'[39] data from different sources. This will also heighten the researchers' interpretations and strengthen the rigour of the data.

The three broad themes of data analysis are:

- Coding data so that themes are placed together.
- Integration of themes into categories.
- Theoretical saturation.

Considering there was a mix of 'Framework' and thematic grids, the following section will discuss these two methods.

Identifying themes

It was important to be familiar with transcripts to read and listen to them over many times, colour-coding the themes within each of the broad groupings. When the tapes were transcribed attention was paid to how words were being said, and in what context, giving depth and meaning to the words. This was helpful in 'showcasing' patients who found some aspects emotionally difficult to talk about (for example, Jinty when she said she 'could not go on') or the unanimous words of professionals agreeing in focus groups (for example, in Focus Group One, specialist ward, there was a resonance of 'Yes, you do' regarding getting too emotionally involved).

Mason (2005) suggests reading the text literally. She also identifies three ways in which the researcher can categorize the data. The three ways are literal, interpretive and

[39] 'Indexing and charting' refer to the stages in 'framework' (Ritchie and Spencer, 1994).

reflective. When the three ways were applied to this study, literal relates to the content, structure and layout of the transcript. This may be done through focusing on words (see the section on 'Belittling of illness' in Chapter 5 as an example). Interpreting involves constructing what the data may mean (see section on etiquette). There is also reflective reading, which explores the role of the researcher in the process of generating data.

The indexing of themes was inserted with pencil (and highlighted in different colours) along the side of the transcripts. The colours emphasized the ability to 'count' (Richardson, 1984) in a contextual way (who is saying what and why) and in the number of times the themes came up, which also facilitated the collapsing of some themes into another to form categories. This was an ongoing process up to thesis completion. The 'NVivo' computer package was used to help index themes, but then reverted to colour-coding, as the meaning of themes changed so frequently that having a visual representation in colour and by hand was more manageable. Coffey et al. (1996) state that no computer package can absolve the researcher from his or her theorized account. Kelle (1997) also states that even when computer packages are used, many researchers use these alongside a pencil and paper. As stated earlier, a MindMeister computer software programme[40] served two main purposes: firstly, to create an account or a journey of all the changes that had occurred. Secondly, it served as another way to analyse data in a visual way, which was helpful in collapsing themes into categories. Indexing[41] refers to the process whereby the thematic framework is applied to the data in their textual form.

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[40] A MindMeister programme is mapping software which enables data to be visually represented.

[41] 'Indexing' is a term used in 'framework' (Ritchie and Spencer, 1994).

Coding initially involved indexing text into ‘themes’, which were derived from the questioning routes. The charting of themes was then carried out. The charting of themes is to apply a uniform set of ‘categories’ systematically and consistently to the data (Ritchie and Spencer, 1994). Categories were literal, interpretive or reflective (as discussed above). Comparison of the themes generated further insight into who said what and why, attending to *a priori* categorizations from the agenda questions to ‘in vivo’ codes. For example, professional roles changed to ‘etiquette’, which was an in vivo code developed from one of the patient’s accounts. This then allowed me to explore further what purpose professional etiquette served for professionals and why, and in what way within and across each of the wards. This was then discussed further when presenting findings in the dissemination focus groups.

Integration of themes into categories and then codes

The next stage involves comparing the accounts and indexing the themes systematically and consistently within and across other aspects of the indexing frames. As each new category of meaning was selected, it was then compared with others and subsequently grouped together (Mason, 2002). Some themes which were initially defined were made into broader themes or smaller themes as the patterns of codes fitted together. There were overlaps in themes from patients’ and professionals’ data, but they differed (for example, from a clinical versus a social perspective). An example of this is given in relation to ‘emotional engagement’. Professionals undertook emotional engagement, but this manifested in different ways. Patients tended to look to the personal side of the professional, but this was blocked at times by professionals who did not want to get too involved (as a way of protecting themselves). Professionals tended to be paternalistic in

not sharing the truth with patients because patients were perceived as ‘old’ and needing protection. In this example, you can see the theme ‘social aspects of age’ and ‘being seen as a person’ being connected with the categories of being a patient and a professional. Through the interactive nature of the text, tensions of truth-telling emerged. The tensions were caused by the lack of training for some professionals on how to properly break bad news.

The judgements on where and why indexes were provided were made by ensuring that codes were not inferred from one participant, but from the majority (citing exceptions where applicable). The use of thematic grids and indexing text to themes was central in highlighting exceptions or similarities in analysis. It was also important to reflect on field notes to explore any contradictions or thoughts that were missed. Spradley’s (1980) framework was used to help provide a systematic approach[42]. Field notes were typed into individual transcripts. Two quotes from my field notes give examples of this. This first quote relates to pain management on the medical ward:

> I was saddened to hear the pain control was not good on the ward. I then thought that perhaps Alexander was fighting against the belief that older people get pain and then I felt the restriction was in two ways – organizational and from social beliefs (August 2008).

This second quote relates to emotions on the specialist ward:

> I could really understand how Christine felt when she said they were like her family, but she also said that they were all the same, which made me wonder

[42] Spradley’s (1980) framework involves dividing the world into smaller categories such as place, actors, activities, feelings, events and goals.

> was … was it that they were all cancer patients which normalized this 'notion of sameness' or their familiarity? (March 2009).

Transcribing supervision notes was also helpful in the development of thought from the descriptive to the more analytical. This also helped with questioning routes. Similarly, reflecting on the supervision notes acted as an 'aide memoire' of why the nature of codes had changed. This allowed me to put themes into further categories and codes, which became more reflective or interpretive in nature.

Here are two examples of my supervision quotes:

One was earlier, from March 2009:

> There is the normalization, comparing themselves with others, being in the same boat and then the emotion work with the patient. What I suspect is happening for the staff is something not dissimilar, although there is trying to make sense of the person with cancer and all the social stuff. I think there is also some really interesting stuff.... Colonization is a variant of normalization, but it's for staff (Supervision, March 2009).

The term 'colonization' was further categorized into 'notion of sameness' in a clinical and familiar sense.

The other quote was from 2010:

> I thought that the headings were always very helpful, as useful as working headings … but they also need to 'earn their keep' for organizing your argument in the thesis (Supervision, 2010).

The time lapse in the supervision notes demonstrates how the analysis progressed. As the development of my data developed with my field and supervision notes, I developed my questioning routes further.

Developing ‘MindMeister’ maps enabled me to organize themes into codes. This process also helped with hierarchical meaning, categorizing if codes were conceptual or descriptive, and reflecting on whether the data were in relation to the ‘process’ of patients’ accounts or more to the development of a theory.

An example of this was in relation to the in vivo code ‘etiquette’, which was from a patient transcript. After further analysis, etiquette, when applied to professional accounts, was further categorized into informational, emotional and moral aspects. Strauss and Corbin (1998) refer to this theoretical sensitivity as ‘having insight, the ability to give meaning to the data, the capacity to understand and the capability to separate the pertinent from that which isn’t’ (p. 40). While the use of systematic analysis was helpful in refining themes and generating the codes, the role of theory was equally essential in generating an argument.

Analytic insights from dissemination focus groups

Dissemination focus groups provided several aspects of benefit to the study. It affirmed the trustworthiness of data through crystallizing different perspectives of the older person with cancer and the relevance of codes.

The importance of respondent validation ensured authenticity by sharing findings with professionals who had been interviewed. However, respondent validation cannot be a simple test of findings. In addition, Bloor et al. (2001) argues that dissemination focus groups can be a way of generating further data and a way to pursue new paths in the analysis.

Dissemination focus groups further emphasized the strain between social and clinical aspects of disease both for patients and health care professionals. It gave additional emphasis to the tension of being older as a patient as well as a professional.

The dissemination focus groups further 'problematized' the intersection of age/stage and illness, identifying further tensions and potential conflicts from different professional goals of cancer care. Further interpretations were highlighted in interdisciplinary working and various agendas of professionals. Professionals also appeared to be reflective on each other's roles in a positive way, thus the focus group was a therapeutic experience for some professionals. One senior staff nurse commented 'I never heard Janice talking about her role like that – I am really glad I had that opportunity.'

In summary, the dissemination focus groups served to provide analytical insight into the data and to also ensure 'respondent validation'. It also enabled the researcher to acknowledge any 'puzzling patterns' within the data that had emerged and to ask further questions. Having 'new respondents' who had not been previously interviewed helped in providing more insight, as those respondents were coming in 'fresh' to the findings.

Theoretical accounts

Theoretical accounts are essential in making sense of the data, as they are able to interrogate existing data frames. As stated by Coffey and Atkinson: 'Theories are not added only as a final gloss or justification; they are not thrown over work as a final garnish. They are drawn on repeatedly as ideas are formulated, tried out, modified, rejected or polished' (1996, p. 158). Mason (2002) identifies the sequence of the place of theory as seminal to the ontological approach.

The process of generating theory is congruous with the interpretive tradition associated with moving back and forth between data, experiences and broader concepts (Coffey and Atkinson, 1996). Theory was used dialectically, being associated with the interpretive tradition of moving back and forth between data, my experience and broader concepts (Coffey and Atkinson, 1996).

It is important that theory is relational and that the theory that is applied to material is appropriate. Mason (2002) also draws upon the importance of categorizing the data, as it provides an explanation of the data after they are indexed and categorized. This thesis has used both aspects of this theory. The dissemination focus groups served as a further way to add to the theoretical building of data, as professionals gave different insights into the data.

Theoretical saturation is said to occur when there are no new properties that can be added to theory. A way in which theoretical saturation was generated was through my field notes and reflections (from both my past and new data that had been gained through data generation).

Barbour (2008) alerts us throughout the approach to look for ‘the exception that “proves” the rule’ and ensure capitalization on serendipitous insights. This lets the data and systematic process involved ‘do the talking’ rather than resting on assumptions. Examples of exceptions to the rule or negative cases were significant in refining the theory. A patient wanted to know her blood pressure, but professionals did not want to communicate this to her. Another lady who was a past nurse in the ward wanted the professionals to be truthful

with her. These accounts highlighted the ‘power’ aspects of the professional stance, while patients wanted more control but showed this in different ways.

In summary, theory has to be continually tried out, tested, rejected or polished (Coffey and Atkinson, 1996). Theory was seen as being developed at the same time as the data, which were congruous with the ‘interpretive’ theoretical underpinnings of the thesis. In conjunction to theoretical insight it was important to also discuss analytical insights from the dissemination focus groups, which augmented theory further.

Challenges in the analysis

This section will present the challenges that were faced in the analysis. Throughout my study, I attended and presented at national and international conferences. The presentations served as a real opportunity to ensure trustworthiness and rigour in my analysis. Presentations and ongoing reflections also served as a constant check on how codes were developed.

Barbour (2008) advocates that analysis is about acknowledging bias and being reflective on where we are as researchers with our own backgrounds, experience, values and beliefs, and making these transparent (see section on reflexivity earlier in the chapter).

The way analysis occurred was through note taking, reflection, and noting clearly how themes emerged from *a priori* in vivo codes. Continually thinking of analysis even when not near a computer was seminal for reflection. Continually writing down thoughts in notebooks enabled insight into thought processes. Reflection of supervision transcripts enabled an audit trail of how themes emerged, were refined, and connected to one another.

As discussed earlier, initially a computer analysis was used, but then resorted to paper and coloured pens. This made the data more real to me, as links were visually made, which is not so easy though a computer package. Reflection on data was also facilitated through discussions and presentations at national and international conferences, which were not solely about nursing, but emphasized the connection between nursing and sociology[43].

Another challenge in data analysis is vulnerability through misrepresentation. This can occur when changes to punctuation of transcripts occurs, thus blurring the transparency of accounts. As discussed already, listening to the tapes as well as reading the transcripts enabled visualization of the context in which people were talking. Field notes gave insight into some of the non-verbal messages in all interviews. Barbour alerts us to the fact that the language used can bring out the hidden beauty of being with and 'worrying away' at the data – who is saying what, and how. Two examples of the 'how' were in comparing how George used the metaphor of professionals being 'highbrow' as he did not understand what they were saying. In contrast, David saw professionals as 'God-like'. Their images portray different meanings through the language they use and how they said it. While recognising the challenges of analysis in relation to over-coding or misrepresentation of data, it is equally important to ensure there is a true reflection of findings.

Quality and integrity

Ensuring truthfulness within accounts is crucial, as the researcher may seriously breach the respect of interviewees' autonomy through inaccurate interpretation (Wiles et al.,

[43] Medical Sociology Conferences BSA, European Society for Health and Medical Sociology (ESHMS).

2007). Interpretation is based on the interviewer's perceptions and can affect what the researcher hears within the text. Considering interviewees' stance of accounts – for example, which perspective they were talking from, and the effect of the situation on their accounts – acknowledged the multiple perspectives in linguistic accounts. Generating data acknowledges a version of the truth, but can never describe the lived experience of another (Wiles et al., 2007). The remit of confidentiality and ground rules was outlined as information was given in relation to the handling of anonymized data. Being aware of not doing harm or coercing participants helped ensure good quality research was being carried out. Awareness of interacting with the participant and the multiple meanings that can arise from the process of interaction heightened truthfulness of accounts.

Reporting findings: selection and presentation of data

Pseudonyms were used for all participants. Details were given of the type of ward, grade, gender, disease and type of data in order to contextualize the quotation for the reader so they can relate to the sampling strategy.

Using verbatim quotations from participants has been standard practice within the social science research domain and predominates in qualitative research, especially when reporting on the views and experiences of those using health services (Mason, 2002; Sarantakos, 2005). However, there have been criticisms of how quotations have been selected and presented (Gilgun, 2005). Some researchers 'cherry pick' quotes, rather than presenting quotations in a way that generates confidence in the study. Readers should see how quotations fit with the analytical approach or how quotations have been selected in

support of a particular argument (Mason, 2002). This study used quotations from transcripts to demonstrate how patients and professionals experience and understand care.

The selection of quotations was made considering the rhetorical functions of the data. The quotations served both purposes. It was important not to let the data speak for themselves because analysis is a systematic process and the researcher has to be upfront in showing their perspective and authoritative presence (Mason, 2002). The quotations were also related to my sampling strategy and theoretical grids, as will be shown in more detail in the analysis chapters.

Seale (2004) and Mason (2002) talk of being 'fallibilistic' about the approach, which means ensuring the analysis is understandable and the process of how one got to this finding is clearly justified. It was important to continually revisit the data to ensure that nothing was missed, looking at it 'from a sideways view' and identifying exceptions. The grids and mind maps were ways of illustrating the approach that was taken.

Quotations were used to reflect who the people were (professionals, patients), the place where they were cared for, and their experiences, disease types and stage. Quotations also reflected processes (how professionals care, using both narrative and physical examples). In contrast, quotes were also descriptive of emotions (experiences, wants, expectations), and were also used in contrasting sequences, looking at different wards together, various disease trajectories from wards. The quotations were used to show purposive sampling, which reflects the diversity of the sample. In presentations, identifiers are given to the audience through colour-coding the quotations. This facilitated the audience's understanding.

Rigour

It is argued that qualitative research has a rich tradition on the quality stakes (Emden and Sandelowski, 1998, 1999). Rigour is the attempt made by the researcher to provide reassurance that the research has been conducted properly and the findings can be relied upon (Seale, 2004; Sinding and Aronson, 2003).

Ever conscious of my own assumptions, as I recorded in my reflective notes, I listened to tapes time and time again and reread transcripts. I also found the reflective accounts from my supervision interviews fruitful. As discussed, I tape-recorded and transcribed all my supervision sessions so that I could reflect on the discussions and look back and forwards to different supervision times. This enabled me to see how the analysis had developed. Records of the 'MindMeister' maps also helped to show how the codes had changed. Particular aspects which challenged my assumptions and invoked feelings of surprise, sadness or satisfaction were reflected upon. I also 'counted' as I analysed, looking to some questions such as 'Why did I feel that emotion?' 'Was it related to my past experiences as a nurse, mother or lecturer or was it caused by none of these attributes?' While being rigorous in analysis and being reflexive is essential, it is also important to show the validity of the research.

Validity

Silverman (1993a, 1993b) recommends five approaches to improve validity: application of the refutability principle; use of the constant comparative method; comprehensive data treatment; identification of the deviant case; and the use of tabulations. Hammersley (1990) states that they do not provide fool-proof validity, but promote confidence that 'an

account accurately represents the social phenomena to which it refers' (p. 57). Validity requires that all the multiple perspectives be taken into account rather than accepting the limitations of one perspective. Porter (2007) discusses the importance of judging competing approaches to qualitative research and ensuring accounts are as accurate as possible. It is highlighted by many authors that validity is linked to trustworthiness (Sandelowski, 1993; Pawson, 2003) and that researchers have a role to play in writing a persuasive and coherent account of findings. I will outline ways in which I ensured rigour in the study. In developing my account, criteria identified by Pawson (2003) have been used. He talks of questions relating to transparency, accuracy and purposivity. The questions and responses relating to this study are given below.

Transparency: is the process of knowledge generation open to outside scrutiny?

I developed methodology appropriately from the gaps in literature. This allowed me to follow certain stages of the research process through a clear plan of data collection and analysis, as outlined in this chapter and the analysis chapter. The rationale for the study has been defined and supported by theory. The process of thesis review is rigorous in the School of Nursing (University of Dundee) with regular supervision, where I discussed the generation of data. Oral presentations were given on a yearly basis.

Accuracy: are the claims made based on relevant and appropriate information?

The findings were continually compared and contrasted to studies from the literature review and other newer studies as analysis was developed. The sample that was purposive

sought to generate diversity in accounts. Sampling grids added to the rigour in analysis. The representative sample was not sought to be generalizable, but rather to be transferable to similar groups. The data were generated, indexed and charted in a systematic way and checked for deviant cases. Charting using grids enabled 'counting' who said what and why. Using the theoretical grids allowed for the comparison of interpretations, the discussion of alternatives and the refining of coding frames to reassure the reader that analysis has been systematic (see Appendix G).

Purposivity: are the methods fit for purpose?

It was of utmost importance to ensure that the approaches to data generation fit the research design. The choice of methods was made by looking at the available methods and analysing how they fit with the theoretical underpinnings of the study. It was also important to explore the shared knowledge that sources would feasibly tell me. I considered how I could do this epistemologically – through social construction. I then looked to my research questions and considered what methods could best be addressed. Dissemination focus groups were another way of adding rigour and validity to the study.

Reflexivity in action

Reflexivity is a term which is used within social constructionism as well as within qualitative methodologies e.g. phenomenology. Reflexivity also refers to the equal status between the participant and the researcher. Reflexivity affirms that the researcher is shaped by their experiences of the situation or their interactions (Gilgun, 2011). There are various sources of reflexivity relating to:

- My previous understanding of the older person with cancer and previous experience of care settings when caring for the older person with cancer.
- Interrogation of the data through an in-depth systematic analysis showing transparency.
- Analysis of data with the social constructionism underpinnings of the study, which were hidden from the participants.
- Acknowledgement of the influence of organizational structures and the contextualization of meaning within each of the ward settings.
- Perceptions of professionals' norms and behaviour, which may constrict true understanding of older people with cancer.

When analysing data it is important to interpret the original data, as well as aspects which are not present in the data, such as a researcher's own understanding and the philosophical intent of the current study. The 'multiple voices' as sources which inform data generation are summarized in Table 2:

Table 2: Sources which informed data generation

Sources which informed data generation
My supervisors; Ethics. *[44]
My experience as a lecturer, nurse in a variety of settings, woman, mother and carer. *
Field notes on each of the wards during and after each interview. **[45]
Participants (patients) within each setting through interviews (seeing themselves as patients, people, women, men, mothers etc.). **
Participants (professionals) within each setting (seeing themselves as patients, people, women, men, mothers etc.) **
Professionals' perceptions given through interviews, focus groups and dissemination focus groups. **

The table is not meant to be seen as linear, but rather as an iterative process referring to both my prior understanding and new data.

To signal reflexivity, I used the first person. This is congruous with qualitative tradition (Gilgun, 2011). Using the 'I' word also acknowledges that the researcher is a person who also experiences the interview. Bruner (1986) pointed out four themes of consciousness.

[44] Indicates pre-understanding *

[45] Indicates new knowledge **

These are:

- Researchers experiencing themselves,
- Researchers experiencing informants,
- Informants experiencing themselves, and
- Informants experiencing researchers (p. 14).

In this study, I tried to unpack these themes of 'consciousness'. From listening to the interview tapes and being reflexive, I tried to acknowledge the multiple 'lenses' that I used to perceive the data. The following section will discuss these four themes of consciousness when applied to this study.

Researchers experiencing themselves and researchers experiencing informants

The data generated have to be considered in a way that allows for reflection back on one's self. My personal and individual biography influences the description and interpretation of the transcripts. My professional past and present roles in education and as a senior nurse in various roles within an oncology setting alerted me to the need for older patients to be cared for in a way that is fair and equitable to others. As a daughter, I cared for my mother and father until the end of their lives (both died of cancer while I was generating the data during this study). This gave me further insight into the emotions of hospitalized patients, enabling me to think of them as people 'who could have been my parents'. My past, professional and personal experience allowed me to more fully appreciate both the person side of the patient and the person side of the professional. This was particularly pertinent for me when I interviewed a patient who knew my father when he was a practising

optician (like my father, the participant was also Italian), thus acknowledging the multiple realities of life that can emerge while generating data. When speaking to the participants I was aware of the multiple roles that I have as a researcher, and of the fact that I was a woman, mother, wife, researcher, lecturer and nurse.

Gilgun (2005, 2011) reminds us of the importance of recognizing ourselves as embodying various roles, such as researchers and women. In interviewing men who had raped women, she explains how she also recognized violence in herself when she envisioned inflicting pain on the rapists as a result of hearing their accounts. In a similar vein to how Gilgun (2011) reflected on her thoughts during interviews, when interviewing participants I found myself empathizing and thinking of my past experiences as a nurse or carer for my parents. This allowed me to demonstrate mutuality with participants. Thus, the influence of multiple roles between the interviewer and interviewee is critical and must be acknowledged as an ongoing iterative process. When looking at data and interviewing others, it is important to be aware of one's 'lens' as a researcher.

Informants experiencing themselves and informants experiencing researchers

None of the patients had been interviewed before. Participants who wanted to be interviewed appeared to appreciate the opportunity to discuss their multiple identities as a mother, father, wife, husband, man, woman, cancer patient and older person. Many of their accounts were based on cultural stereotypes of being an older person, and they therefore often perceived themselves as undeserving of treatment and perceived younger people with cancer as worse off. Some patients identified with the social norm of being a

mother or father by protecting their family from the true impact of their illness. Others referred to their past losses to make sense of their present situation.

Similarly, professionals referred to their roles as a carer for their mother or father and/or their own past losses to make sense of how and why they perceive the care they deliver. As patients discussed these multiple identities, I reflected on why there was a particular emphasis on one perspective rather than another, and why patients saw themselves in certain ways when engaging with professionals. They appeared to see me as an intermediary person who was not clinical, even though I informed them in the consent letter that I worked for the School of Nursing.

Reflexivity is related to achieving an understanding of the nature of the social reality from an individual perspective. Accounts are embedded in prejudices and so demand a self-reflexive manner in interpreting text. The nature of an account from patients or professionals is a description of the event. The researcher cannot then believe that his account is the only perception of that account; rather he must provide a platform for further discussion through looking at the multiple realities.

The very nature of a social constructionism ‘problematizes’ assumptions that are taken and therefore by its very nature facilitates a reflexive process. There were differences in the context, language and text used by different professionals. The focus of care and culture of the ward setting and prior conceptions held by the researcher all added to the continually changing approach. Thus, it was important to consider the individual accounts of the other ward transcripts and then what meaning was generated. In summary, a researcher experiencing themselves, a researcher experiencing informants, informants experiencing

themselves and informants experiencing researchers was a continual cyclical reflexive process that helped to tease out the multiple perspectives.

Findings

Sample characteristics

This sample is based on two pilot focus groups (one in each of the wards), ten in-depth interviews with patients (five patients from each ward), ten in-depth interviews with professionals (eight of whom were permanent members and two who visited each of the two wards), and three dissemination focus groups[46] (which included a range of permanent and visiting professionals). Five professionals had worked on both wards. Four professionals who were interviewed attended the dissemination focus groups. One professional attended an interview, focus group and a dissemination focus group. Engaging with patients and professionals provided many opportunities to compare and contrast different perspectives relating to the care of the older person with cancer. It was acknowledged that there was a possible source of bias as past accounts of working in both wards may have skewed accounts.

There were four main data sets which were being compared together as an iterative process. These were:

- Focus group data set – 2 transcripts (1 from each ward).
- Patient semi-structured interviews – 10 transcripts (5 from each ward).

[46] Dissemination focus groups enabled a dissemination of results, a source of member checking and to gain further reflection on data.

- Health care professional interviews – 10 transcripts (4 from each ward, 2 visiting professionals).
- Dissemination focus groups – (2 from the specialist ward, 1 from the medical ward).

The sample therefore was representative of what the study aimed to do. *Sections* are divided into four sample groups: Professional: two focus groups (1), Patient: ten semi-structured interviews (2), Professional: ten semi-structured interviews (3) and Professional: three dissemination focus groups (4) (see Appendix C, which shows sampling grids for interview participants).

1. Professional sample: two pilot focus groups

One pilot focus group was carried out in each of the wards. The sample in the first focus group (specialist) consisted of three registered nurses (all female). All had a course in administration of chemotherapy. One professional was a cancer survivor.

The second focus group consisted of three registered nurses; one had a post registration course in cancer care. One nurse had experience of the specialist ward previously. One had a post registration course in palliative care. Purposive sampling also gave rise to some fortuitous opportunities for comparison. Four nurses from the specialist ward had worked on the medical wards. Two visiting specialists worked on both wards. One of the nurses from the medical ward had worked on the specialist ward. Another example was an interview with someone who was a nurse in the cancer ward and was, at the time of the study, also a patient in the same ward. One nurse in the focus group was a cancer survivor.

Having two visiting professionals to both wards gave another perspective, not being part of the permanent ward team.

2. Patient sample: ten semi-structured interviews

The patient sample on the specialist ward consisted of three males and two females. The age range was from 70 to 82. They were all in the palliative care stages needing supportive care, apart from one patient who was receiving active treatment (David). The range of diseases was: hairy cell leukaemia (1), breast cancer with metastases (2), unknown primary with liver metastases (1) and prostate cancer (1).

The patient sample in the medical ward consisted of three males and two females. The age range was 75 to 82. They were all in the palliative care stages needing supportive care. The range of diseases was: lung cancer with metastases (2), unknown primary (1), prostate cancer (1) and colorectal cancer (1).

One patient had experience on the two wards from both a personal and partner's perspective. His wife had died on the specialist ward that he was now in. One patient had previously had cancer and his wife had died from cancer. Another participant lost his first wife to cancer and his second wife was a cancer survivor.

3. Professional sample: ten semi-structured interviews

The sample in the specialist ward consisted of one male and three females. All professionals had a certificate in delivering chemotherapy (not degree level but competency based).

The sample in the medical ward consisted of four females. The educational qualifications were: post-registration course on cancer (1), post-registration course on palliative care (2), Diploma in Nursing (4) and a counselling course (1).

The two visiting professionals to the two wards included a Clinical Nurse Specialist (CNS) in lung cancer who was undertaking her MSc in advanced cancer care and a Chaplain who had a BSc in Theology.

4. Professional sample: three dissemination focus groups

The three dissemination focus groups consisted of permanent members and visiting staff members.

The first dissemination group sample consisted of three staff nurses. One had experience of the medical ward. All had a competency certificate in chemotherapy. One participant had already been interviewed.

The second dissemination group sample consisted of two staff nurses, an occupational therapist, a dietician and a pharmacist. One participant had already undertaken a semi-structured interview. The dietician was assigned to the specialist and medical ward.

The third dissemination group sample consisted of three females and one male: an occupational therapist, a pharmacist, an education facilitator (cancer and palliative care) and a staff nurse. One staff nurse had already been interviewed and had attended a focus group.

The total sample consisted of the following[47]:

- Patients (10)
- Registered nurses (18)
- Occupational therapists (2)
- Dieticians (1)
- Nursing practice education facilitator in cancer and palliative care (1)
- Pharmacists (2)
- CNS (1)
- Chaplain (1) = 36 participants in total.

How the collection of professional and patients' views informed each other

When interviewing patients and professionals it was important to access multiple perspectives of what was being said, who was saying it and why. Using two methods allowed provision of equal accounts but coming from different people with varying experiences. Employing the two groups of participants at the same time allowed questions to be asked in different ways. For example focus groups can give access to professional public accounts whereas the interviews gave access to the more private accounts. Rapley (2001) warns of the danger in using one type of data collection rather than another, but rather recommends using both methods to provide a multi-faceted account. In this study

[47] Focus groups were analysed 'as a whole'. Therefore if there were three people in a focus group they would be counted as 'one whole'. However, within the focus groups, 'counting' occurred: looking at who was saying what and why: Richardson (1991).

having two data generation methods allowed an understanding of the clinical/social, personal/professional and patient/personal stances.

A qualitative approach made it possible to 'problematize'[48] the older person with cancer through an unpacking of accounts from patients and professionals, looking at how participants make sense of their place of care in hospital. Thus accounts informed each other as themes were analysed together, while also ensuring they were identified as to their characteristics. The example of the sampling grid gives an example of how professional and patient accounts informed each other.

Field notes – and how they were managed

Field notes were used in two main ways as cited by Mason (2002). One is set up into a data set that can be analysed. The other type is set up as developmental devices. In this study both methods were used. The field notes are helpful in incorporating my own thoughts and helping to make sense of the data. In relation to the ontology and epistemology of this study, the field notes are written in an interpretive way, to make sense of a phenomenon under study.

Examples of the questions raised during the writing of field notes were:

- What care interventions did health care professionals routinely perform?
- What interactions did patients have with professionals?
- What are the challenges and promoters to care?

[48] 'To problematize' is to expose and analyse problems in something previously assumed to be without problems.

- What were the characteristics of older patients with cancer within each ward?

For example, field notes about the structure of the wards, the number of side rooms and four-bedded bays, access to information about cancer, visiting times, number of staff on duty, number of consultants and ward round activity gave insight into the context of the ward. These notes were invaluable, as they gave further meaning to themes which related to the structural aspects of the ward environment.

The field notes were gathered before during and after data generation. The field notes were helpful in acting as raw data from an observational and interpretive way. The field notes were typed up with the date. The themes were developed through initial code building. It was helpful to cut the data and place into the themes. Using Wolfinger's (2002) questions enabled an enquiring approach to what I saw or thought. The field notes acted as a way of confirming hunches or unravelling false leads. The field notes, for example, show the developments in thinking from cancer diagnosis to the greater life experience before and after a cancer diagnosis. An extract of the field notes is given in Appendix O.

Staff and patient profiles

See tables showing staff and patient profiles in the different data collection approaches below[49]:

[49] Four professionals had attended both semi-structured interviews and a focus group. One participant (registered nurse from the specialist ward) had attended the semi-structured interviews, one focus group, and one dissemination focus group. One nurse attended all three data generation methods while four attended the semi-structured interview and dissemination focus group. Out of the five participants (all registered nurses) three were from the specialist ward and two from the medical ward.

Table 3: Focus group one (specialist ward)

Pseudonym	Profile
Staff nurse Granger	• Is a cancer survivor • Has level 2 course in chemotherapy • Has level 9 course in cancer care
Staff nurse Knowles	• Had past experience of day care unit
Staff nurse Bell	• Works on specialist ward • Has level 2 chemotherapy course

Table 4: Focus group two (medical ward)

Pseudonym	Profile
Staff nurse Jeana+[50]**[51]	• Works on the medical ward • Worked on ward for nine years • Near retiral • Had experience of cancer care and giving chemotherapy in the past • Undertaken a counselling course
Staff nurse Percival	• Worked on the ward for eight years
Staff nurse Duke	• Works on medical ward • Has level 9 course in cancer and palliative care • Qualified for five years
Staff nurse White+	• Works on medical ward • Worked for one year on ward • Undertaken palliative care level 9 course

[50] + indicated they consented to being interviewed and attending focus groups.

[51] ** indicates that they worked on both wards as visiting 'specialists'.

Table 5: Profiles of professionals

Semi-structured interviews	Profile
Chaplain Forbes** (Visiting both wards)	• Worked in hospital for eight years • Visits both wards
CNS Fenton (Lung CNS)** (Visiting both wards)	• Worked in cancer centre previously • Works on both wards • Undertaking MSc named award in cancer care
Staff nurse White+	• Works on medical ward • Worked for one year on ward • Undertaken palliative care level 9 course
Staff nurse Jeana+**	• Works on the medical ward • Worked on ward for nine years • Near retiral • Had experience of cancer care and giving chemotherapy in the past • Undertaken a counselling course
Staff nurse Jenkins	• Works on medical ward • Has level 9 course in cancer and palliative care • Qualified for five years
Staff nurse Scrimingeour	• Works on medical ward • Worked on ward for five years • Has specialist qualification in respiratory care
Staff nurse Gamlin+	• Worked on specialist ward for three years • Previously worked on the medical ward • Has level 2 chemotherapy course
Staff nurse Kew+	• Works on specialist ward • Senior staff nurse • Undertaking MSc in cancer care
Staff nurse Krise	• Works on specialist ward • Has level 2 chemotherapy course
Staff nurse Jones	• Works on specialist ward • Worked on ward for 7 years • Has level 2 chemotherapy course

Table 6: Dissemination focus group (one) specialist ward

Pseudonym	Profile
Staff nurse Gamlin+**	• Worked on specialist ward for three years • Previously worked on the medical ward • Has level 2 chemotherapy course
Staff nurse Formage	• Worked on specialist ward for 12 years • Undertaken MSc
Staff nurse Forke	• Worked on specialist ward for 8 years • Had previous experience of medical ward (5 years)

Table 7: Dissemination focus group (two) medical ward

Pseudonym	Profile
Pharmacist Verde	• Works in the medical directorate • Dispenses and manages medication on the medical ward
Occupational therapist Rosa	• Works in the medical directorate • Newly qualified
Dietician Marone**	• Works within medical directorate and attends both specialist and medical ward
Staff nurse Percival	• Worked on the ward for 8 years
Staff nurse Jeana+	• Works on the medical ward • Worked on ward for nine years • Near retiral • Had experience of cancer care and giving chemotherapy in the past

Table 8: Dissemination focus group (three) specialist ward

Pseudonym	Profile
Pharmacist Luca	• Works on specialist ward and prepares and dispenses cytotoxics
Education facilitator Troon (cancer and palliative care)**	• Delivers short courses in cancer and palliative care to all general nurses in the hospital • Worked on the specialist ward for 18 years
Staff nurse Kew+	• Works on specialist ward • Senior staff nurse • Undertaking MSc in cancer care
Occupational therapist Passat	• Works on medical ward • Two years qualified

Table 9: Profiles of patients

Pseudonym	Profile	Clinical	Social
Mary	• Specialist ward • 82 years old • Breast disease with liver metastases • Married	• Bed bound • Fatigue • Bone pain • Tinnitus • Patient had infection	• Retired teacher (deputy head) • Expert patient • Has one daughter
David	• Specialist ward • 78 years old • 'Hairy cell' leukaemia • Undergoing chemotherapy	• Help with mobility • Support for chemotherapy • Weight loss • Breathless • Previous myocardial infarction and cardioversion	• Lived nearby • Does not drive • Past retailer • Girlfriend had Hodgkin's disease • Past wife died of cancer
Colin	• Specialist ward • 78 years old • Prostate cancer • Previously had leukaemia	• Pain • Insomnia • Patient in pain	• Previous painter • Wife died of cancer on same ward
Graham	• Specialist ward • 72 years old • Liver metastasis	• Pain • Fatigue • Nausea • Low in mood	• Past miner • Has wife, son and daughter

	(unknown primary) • Patient in pain and investigation	• Patient catheterized	
Jinty	• Specialist ward • Breast cancer with metastases • 72 years old	• Has pain • Had lymphoedema	• Lives alone • Does not speak to family members • Past nurse on the ward
Janet	• Medical ward • Housewife • 78 years old • Lung cancer with bone metastases • Breathlessness • Arthritis	• Fatigue • Immobile • Breathless • Bed bound	• Lives alone • No family support • Has two daughters • Has two granddaughters
Bertie	• Medical ward • 82 years old • Unknown primary	• Patient had head and neck pain • Bed bound • Catheterized	• No family • Lives alone • Lost contact with family members • Lived in bed sit • For referral to small rural hospital
Alexander	• Medical ward • 75 years old • Prostate cancer	• Bedbound • Pain • Fatigue • Anorexia	• Lives with wife • Has a dog • Loves bowling
Andrew	• Medical ward • 80 years old • Colorectal cancer • Retired painter	• Pain • Anorexia • Depression	• Golfer • Has two sons and carer for grandchildren
Ruth	• Medical ward • 78 years old • Housewife • Lung cancer and metastases	• Breathless • Pain	• Lives alone • Has daughter who lives nearby

Summary

This chapter has addressed the methodological choices made within the present study through describing the research process as being iterative. The ontology and epistemology were described, as well as how this framed the data generation choices and the analytical process, which was congruous to this qualitative study. Reflexivity and rigour of analysis were used in order to produce a trustworthy piece of research. The following chapters will present the findings from the analysis, illustrating patients' and professionals' perceptions of care delivery within two ward settings.

The next two chapters will discuss the findings of the research, focusing on the care environments in which care is delivered, demonstrating findings from professionals' accounts of the challenges, the impact on care delivery, and how patients experience their care.

CHAPTER FOUR

A Study of Two Caring Environments: the Experience of Care

Introduction

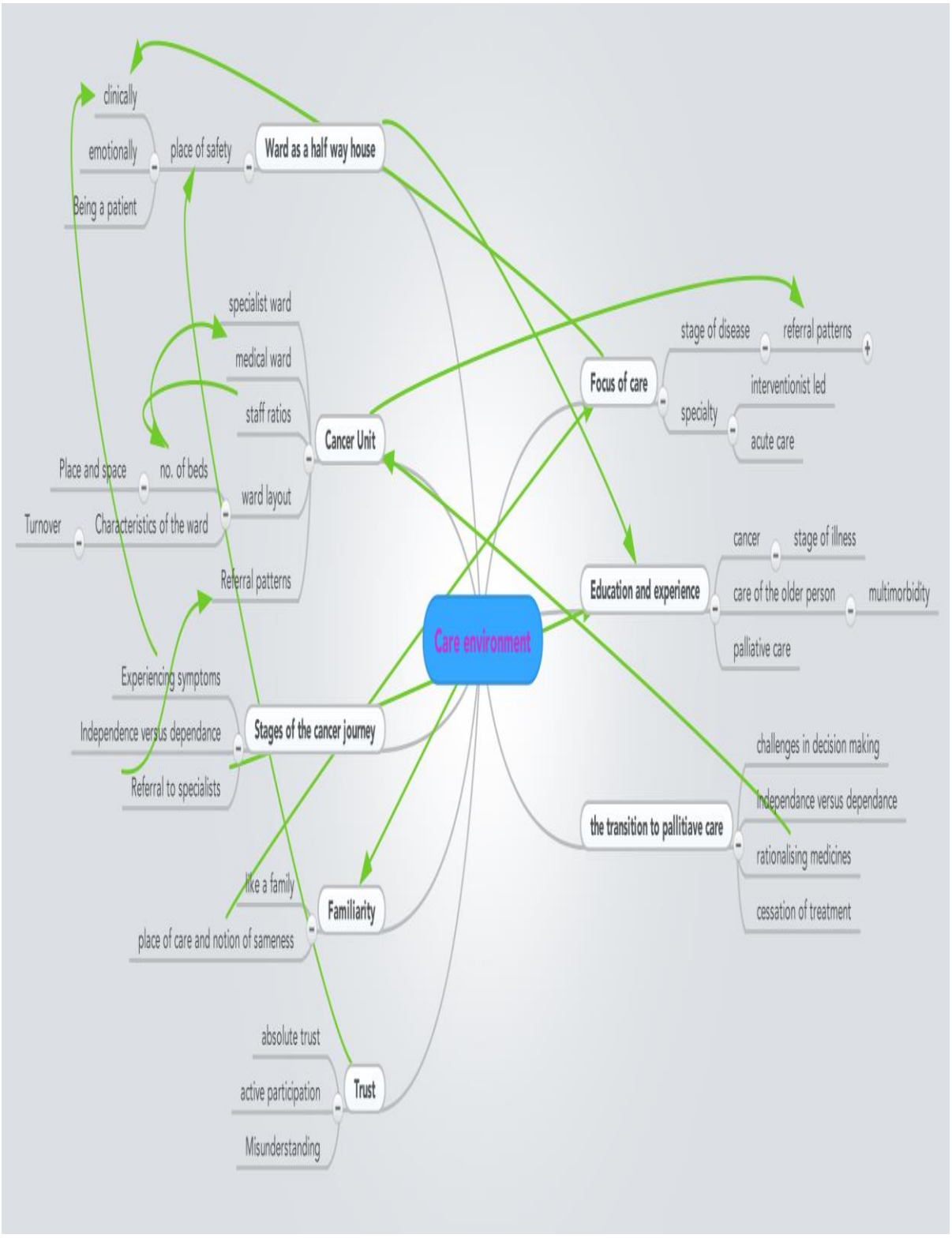
The previous chapter gave an in-depth account of the theoretical underpinnings of the study: the ontological stance and epistemological stance of social constructionism, data collection and analysis. This chapter presents findings relating to care delivery within the two ward settings.

This chapter will explore the two care environments which provide a means for delivering care. There are eight major themes. Firstly, the regional setting, cancer unit and characteristics of each ward from a geographical and workload perspective demonstrated how the therapeutic relationship is influenced through the context of care. Secondly, the focus of care underpinned *how* care was delivered whether interventionist or supportive. Thirdly, the 'ward as a halfway house' explains how the care setting was seen in either a clinical or emotional sense. Fourthly, the theme of trust discusses how the notion of familiarity and/or the discourse of paternalism can highlight how patients felt a range of entrustment. The fifth theme of familiarity reinforced the 'ward as a halfway house' in an emotional sense for patients but also in the notion of sameness 'all being cancer patients' in the specialist ward facilitated care delivery. The sixth theme, stages of the cancer journey, explains the complexity of patients' needs and challenges for professionals as

they experience symptoms, oscillating between independence and dependence, multimorbidity and the importance of referral to specialist nurses. The seventh theme relates to education and experience, concentrating on the experiential and educational attributes of the professionals. Finally, the eighth theme, the transition to palliative care considers the challenges of the focus of care and the challenges of ensuring the timely introduction of palliative care.

Table 10 illustrates the themes from the data and how they relate to one another.

Table 10: 'MindMeister' map: care environment



Characteristics of the study setting

Regional characteristics

Statistics relating to the incidence of cancer over 65 demonstrate that Fife NHS Trust has a similar incidence to other regions. Over the years from 2005-2011 the average admission rate ranged between 1286 and 1906 patients a year. Cancer types within each of the wards varied (see Appendix M). Inpatient lymphoid, breast, male genital, thyroid, were admitted to the specialist ward. Patients with trachea, bronchus were admitted to the medical ward. The specialist ward had 100% occupancy of cancer patients, while the medical ward had 5% occupancy of cancer patients.

Cancer unit

The hospital was situated between two major cancer centres. The general hospital was categorized as a 'cancer unit'[52]. Most of the patients within this small town who had a haematological illness went to the regional cancer centres for their radiotherapy (as this is not provided in a cancer unit). However, if they needed an emergency admission or routine chemotherapy they would attend the specialist ward in the cancer unit. The rationale for admission was categorized from the symptom rather than disease or age category. While the purpose of admission was related to their symptoms, the ward layout

[52] This categorization is a clinical one, which implies that there are restricted choices for treatment for some less common cancers. There is also a lack of access to oncologists who deal with patients with cancers on a regular basis or treat less common cancers such as head and neck cancers. Patients with less common cancers are generally referred to a cancer centre.

gave further meaning to the clinical space and insight into the process of care delivery thus reinforcing the contextual nature to care delivery.

Staff ratios differed between wards thus highlighting the differences in skill mix within each of the wards. See the table below which demonstrates the differences:

Staff ratio (medical ward) 30 bedded ward	Staff ratio (specialist ward) 18 bedded ward
62%-68% registered nurses with 38% to 32% health care professionals Morning shift: 6 professionals, 2 auxiliaries Evening shift: 4 professionals, 1 auxiliary	70%-78% registered nurses with 30% to 22% health care professionals Morning shift: 4 professionals, 2 auxiliaries Evening shift: 4 professionals, 1 auxiliary

From the figures above it is noted that there were more registered nurses present on the specialist ward (in relation to patient numbers) than on the medical ward but the number of staff were not relational despite an increase in patient numbers on the medical ward[53]. This was a significant finding which illustrates why activity within the wards were busier in the medical ward in comparison to the specialist ward.

Ward layout and characteristics

The medical ward was primarily a respiratory medical ward with 30 beds for emergencies

[53] Staff and patients on the medical ward commented on staff shortages.

(who were mainly over 65). The ward also admitted patients with solid tumours but mostly had patients with a primary or secondary lung cancer who were in the palliative stages of the disease. The medical ward had the most dependent patients situated near the nurse's station. It had seven four-bedded bays and two side rooms. It also had a relatives' room. Findings identified that all older patients with cancer in the medical ward who were in beds distant from the nurse's station were not seen as such an emergency in comparison to patients who were admitted with exacerbation of asthma.

The specialist ward had 18 beds and admitted patients with haematology diseases and solid tumours, such as breast and colorectal patients, from a wide age range (17 years old and up). It had 14 single rooms plus a four-bedded bay.

In sum, these findings give insight into the factual data which allows an exploration of the place in relation to care delivery. The organizational systems were different within each ward; bed numbers and clinical types of patients. This created a 'ward culture' particular to each ward. This will be discussed further in the next section.

Specialist ward

In the specialist ward, staff members worked closely with the haematology outpatient unit, which was adjacent to the ward area. The adjacent unit admitted 'day cases' for chemotherapy and for supportive care. This was helpful for the older patients with cancer, because they often knew the inpatient staff, as they went between being outpatients and inpatients. An example was David:

> It is great, as we know the day staff and ward staff – I always say hello when I return to the day staff. They are all angels. (David, leukaemia, specialist ward)

The layout of the specialist ward with its individual rooms encouraged the opportunity to unite both clinical and psychosocial interventions earlier, as the following quotation from the chaplain highlights:

> I can more easily access patients in the specialist ward in terms of rooms … offer contact with a greater percentage of contact than in the medical ward ... [I am] more involved here [specialist ward]. (Chaplain Forbes)

The staff also acknowledged that the specialist ward provided a more tranquil environment, despite the acute[54] clinical care required:

> It's, sometimes you can feel it is really busy, but there is a lot going on and not enough hours in the day to [do] everything and that's not a good place to be, but coming up here [the specialist ward] you still have the same business, but the tension is not [about] who [is] there; it's a more, okay, let's do this and there's a less oppressed atmosphere about it, I think. (CNS Fenton, lung clinical specialist nurse)

These two quotations were from visiting professionals who saw the differences from both a geographical *and* workload perspective.

Medical ward

Professionals supported the view that side rooms gave more privacy, especially when patients needed time and space to deal with their emotions:

> You would try to get them [older patients] into a side room … they need the privacy to deal with it … discuss it to get your families to discuss it and now you

[54] The term acute relates to care which is complex such as the clinical management of oncological emergencies.

> are at a time to deal with it and it makes a big difference. (Staff Nurse Jenkins, medical ward)

Similarly, findings from some professionals in the medical ward suggest that side rooms may allow for this social engagement with professionals, as there is more privacy and less noise, which may facilitate a therapeutic relationship with professionals that could be lessened in a bay. While some professionals in this current study felt that side rooms could serve as a psychosocial space, from a patient perspective, some felt that the lack of interaction could lead to the deterioration of, and loss of the will to live, in older patients in the later stages of their illness:

> As soon as we get them into a side room, older patients can turn their back to the wall, not speak and just shut down. (Staff Nurse Jeana, focus group 2)

Thus, it could be argued that the *layout* of the medical ward – as made up of four-bedded bays – might enable therapeutic opportunities. The specialist ward had more side rooms, which was perceived as enhancing the *therapeutic* relationship with staff members. There were both advantages and disadvantages to the four-bedded bays and single room occupancy. The aspect of *place and space* appears to affect the ability to 'be with' patients, not only in a physical sense but in the sense of creating an environment for a therapeutic relationship. It could be argued that single rooms enhanced isolation due to patients having less interaction with others while also being physically dependent on professionals.

From a geographical perspective, being cared for in a cancer unit may have hindered holistic assessment, resulting in care that was not always coordinated, as can be seen in the testimony of these patients:

> Nobody had told anybody it was cancer. Dr Fairbairn found out for himself. The man at Dunvegan did not notify my GP, did not notify Dr Fairbairn or anybody. We don't know where all the bits and pieces of the ultrasound went (Alexander, prostate cancer, medical ward).

> We just have to wait … I do not know what is happening here … but we are lucky and these people [nurses] are to be respected … (David, leukaemia, specialist ward).

While the cancer unit was described as a 'fragmented system' due to a lack of coordination of care from a social perspective, the location of the general hospital (cancer unit) was seen as a 'friendly place':

> Thus, while there was a fragmented clinical system at times, there was also a familiarity of place and faces, which has proven helpful in generating a 'sense of knowing' to facilitate mutuality between patients and professionals (field note, October 2008).

From a patient's perspective, this *familiarity* appeared to be related to past experience of being in the hospital and knowing the staff on the wards. While the social perspective enabled a sense of knowing, from a spatial perspective, the ward layout, including access to single and four-bedded bays, gives further insight into familiarity with patients. From a professional perspective, familiarity with patients helped create a therapeutic culture. These aspects are important considerations focusing on the interactive elements to care. Importantly however, is the *focus of care* which underpins where patients are cared particularly the *admission process* and the *turnover of patients*. This will be discussed in the section below.

Focus of care

This section will compare and contrast wards in relation to the focus of care. The medical ward mostly admitted patients needing supportive care but often discharged older people to another place of care when they required end of life care. As the professionals on the medical ward managed many specialties, the supportive care experience was more *transient* in nature, while the specialist ward cared for all malignant conditions over repeated occasions, which enabled a more projected supportive care experience.

> You've got to get them in the right direction, what's best for them – going home with palliative care or into a hospice and that's what they need (Staff Nurse Jenkins, medical ward).

This is in contrast to the specialist ward:

> R1[55] I know what you are saying is true; we do get the same patients in time after time and so you get to know them and their families. We try to readmit them here. (Staff Nurse Gamlin, specialist ward, dissemination focus group 1)

> R2 Especially the patients we get in here for prolonged periods of time for months on end. (Staff Nurse Formage, specialist ward, dissemination focus group 1)

Mary (82) with breast cancer stated how reassured she felt as she had known professionals over a long period of time. The social sense of *familiarity* gave patients company and enabled them to talk with professionals. This was more prevalent on the specialist ward, as professionals talked about 'getting to know' patients and so facilitated the social aspects of their care. The nature of the admission process generated familiarity, as it was expected

[55] R1 and R2 relate to responses in sequential order.

that their admission would be repeated. The medical ward, on the other hand, had a higher turnover and less time to get to know the patients socially. These findings are important, in that older people need more time taken to interact socially: in a life mostly lived, these aspects of life may have greater significance than being ill. Relating to them socially would give them more of an identity than being seen as a set of symptoms to be clinically managed. The medical ward was mainly for emergency admissions, when patients were not able to cope at home: the pace of activity was therefore faster, which determined the relationships that staff could build with patients.

Due to the different conditions of the wards, having insight into the total care pathway was less of a priority in the medical ward, where the focus of care was more on how to get patients to the next place of care, rather than on their rehabilitation or self-management. Thus, the medical ward was perceived as a 'holding bay' rather than a destination for care:

> We get a lot of respiratory cancers; our focus is mainly on chest problems … you never know who is coming through the door … the turnover is high … (Staff Nurse Jeana, medical ward).

As a result of the *high turnover*, patients often were moved to another ward. Bertie discussed how he did not want to leave the ward but knew this could not be his final destination due to the priority of bed space. To further complicate, the specialties of the wards within this study were neither cancer nor gerontology. Rather, the older person with cancer appeared to be mixed in with the rest of the ward and had no clinical focus which met all their needs. This also applied to the specialist ward, in that gerontology was not explicit in assessment of their needs. Despite there being no appropriate focus of care for participants, they appeared to become familiar and reassured by knowing others.

The next section will discuss an 'in vivo'[56] code, which explores how patients and professionals perceived the ward as *'a halfway house'*, demonstrating how the two wards managed the transitions of patients.

The ward as a 'halfway house'

This section will discuss patient and professional experiences, comparing the two wards. Patients from both wards experienced 'transitions'[57] relating to changes in treatment, symptoms and how they perceived their quality of life. The ward settings allow patients to feel clinically safe while being symptomatic and unable to cope at home. The theme also describes the concept of feeling clinically safe yet living with uncertainty and adapting to transitions in their illness. The major themes of 'the ward as a halfway house' encompass the sub-themes of 'place of safety', 'being a patient' and 'place like home'.

Place of safety

The need for psychosocial support was essential in supporting patients through these stages. Some professionals saw it predominantly as a clinical space for patients, while others saw it as a 'halfway house', linking clinical *and* social domains of their lives.

Conceptually the wards were seen by patients as a safe place in a clinical sense. The fact that the patients on the specialist ward could self-admit promoted this sense of safety, as

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[56] Words of the respondent(s) can be so descriptive of what is going on that they become the designated code. These descriptive words provided by respondents are what have come to be known as an 'in vivo code'.

[57] Transitions are defined as ongoing processes characterized by change for the individual (Olsson, 2002; Duggleby et al., 2010) during which a new situation or circumstance is incorporated into their lives (Kralik et al., 2006).

well as empowerment through patient self-management. The first quote is from David, who is undergoing chemotherapy and coping with the side effects of his treatment.

> 'Will I be safer to be here, or in my own house?' And, ironically, you always feel safer going to hospital and when you are here you want to go home. (David, leukaemia, specialist ward)

The issue of safety was prevalent amongst patients' accounts, with many feeling reassured by the professionals' clinical expertise:

> I feel safe. I feel safe because I feel that they care about me and they are really concerned about me … just to know that you know you've got to get in because you've got a temperature, etc., and all that kind of thing it just makes me feel, in the hospital environment, safe. (Jinty, breast cancer with metastatic disease, specialist ward)

It appeared that being clinically safe was also related to being psychologically safe, as reflected in the words of 'they care about me'. From the analysis, patients who described the ward as safe knew the staff from previous admissions. There was also a sense of being safe that related to trust in professionals. Another aspect of safety related to protection from the place where patients lived.

Some patients felt reassured by being in the ward as a result of their illness because they were not always 'socially safe' at home due to their poor social conditions. Ruth, who lived alone in a deprived area, recounted a frightening experience where she was threatened by youths:

> And I have got druggies, dealers down the stairs from me, and it is all elderly people. They come up every day for their drugs. They come up to me, and I opened the door, not thinking, and 'Give me money.' I said, 'I don't have any' so I went to shut my door and he put his foot in it, shoved the door on me and I

> had a face like that. He said 'Your car windows will be smashed tonight.' (Ruth, lung cancer, medical ward)

Due to the early death of her husband, Ruth had to bring up her children from an early age alone. Jinty and Bertie had no family members and felt lonely and isolated at home. Most patients talked of feeling more 'emotionally safe' on the specialist ward due to their familiarity with the professionals. As stated above, being a patient added to feeling safe, relinquishing responsibilities out with the hospital, and gave a sense of psychological comfort. In sum, patients in the specialist ward felt a safety in relation to familiarity and staff expertise. Patients in the medical ward did not express sentiments of familiarity being comforting but being more grateful at not being a burden to their families and being safe from social pressures outside of the ward.

Professionals did not perceive that patients would see the ward in this way. Rather professionals in the medical ward saw the ward as a safe place for patients in the clinical sense. In the specialist ward professionals saw the ward as a clinical and emotionally safe place for patients due to familiarity.

'Being a patient'

Being a patient had various dimensions depending on the stage of the cancer journey, the type of cancer and the context of care. There were different meanings to being a patient, including being an older person, a cancer patient, a lung patient and/or a haematology patient.

Mary was coming to the end of her life and was being readmitted because of an infection. She lived with her husband and they had a daughter who was getting married in the

coming months. Despite her family duties at that time, she found it reassuring to be hospitalized, seen as a patient and able to relinquish her other identities within the family:

> I would like to be at home, but as long as you are feeling that, 'No, I couldn't be bothered' … I want to be here, so obviously I feel this is great and I don't feel lazy. I've been given permission, if you like, when I'm here, to lie back in the bed and read. Just, 'Do you want a cup of tea? I'll get you a cup of tea. And here's your dinner.' It's just, yes I feel, it's official, you're unwell and you need care. (Mary, breast cancer with metastases, specialist ward)

Some patients were also relieved from what they viewed as the burden of being cared for by family members:

> Well, my wife has had to struggle with me when I was at home. When you are getting a shower, drying me, washing me, bathing me, my hair – the lot. So she was doing all that. Now I am getting the same help here but they are more professional than my wife is. (Andrew, prostate cancer, medical ward)

This study suggests that hospitalization can invoke not only feelings of being clinically safe, but also allow patients to temporarily surrender responsibility to other duties within their lives while dealing with particular stages of their illness. For some patients, having cancer led to a re-evaluation of their roles within their family – either on a short-term or long-term basis, depending on whether they were entering an acute phase (involving, for example, infections which would resolve), a supportive phase, or a palliative stage of their illness (both of which involved deeper reflections about their future).

From another perspective, patients often felt reassured that the ward provided a place where they could talk to staff and deal with the feelings that they might not express to their family:

> We see them that much and know so much about them and they know so much about us as well. But we see them differently from what their family does; we have a different perspective which I think can bring them a lot of comfort as well. (Staff Nurse Noon, specialist ward)

Staff Nurse Noon highlighted that being in hospital can relieve patients of their social duties within their family while allowing them to disclose emotionally to professionals:

> It helps them … that you're not part of their family. It brings comfort to them because obviously the family are grieving almost as well, so they have the added stress of that, whereas when they are surrounded by us they can be completely honest, they don't have to worry about their families' feelings. (Staff Nurse Granger, focus group 1)

> The good thing is that I can just talk, let out my worries, and know I can be listened to while everything is going on around me. (Mary, breast cancer with metastases, medical ward)

While professionals on the specialist ward felt patients could talk 'safely' rather than burdening their family, professionals on the medical ward wanted more time to talk but felt restrained due to organizational pressures. This was further augmented by a lack of familiarity. A major factor in participants expressing themselves related to the trust they felt for staff. The nature of trust was generated through the 'notion of familiarity' with patients' expectations and beliefs in trusting professionals' advice and care.

Trust

Trust was a theme which emerged as salient for both sets of participants. Patients and professionals perceived trust in different ways, depending on their differing perceptions of being old. Some patients placed trust in professionals, as seen as 'all knowing'.

Others felt more trust when they received information that facilitated self-management. The themes from the major code of ‘trust’ are ‘absolute trust’, ‘active participation’ and ‘misunderstanding’.

Absolute trust

Participants conveyed an overall appreciation and frequently alluded to placing unconditional trust in staff. Some participants never questioned treatment and information given from professionals. Some described professionals as ‘angels’ (nurses) or ‘God-like’ (doctors). Other participants described how they had built their trust for professionals as a result of previous admissions or from caring for other members of their family.

> It’s talking to the staff, respecting the staff and listening to the staff. They know things we just don’t know. (Bertie, unknown primary, medical ward)

Bertie was accepting of medical expertise despite stating his uncertainty about his illness. Overall trust for the medical profession was also perceived as being a characteristic of older people.

However, some professionals in both wards saw their age as an explanation for their illness, thinking that they had had a good life and that death was inevitable, meaning that they were more accepting of ‘their lot’, more subservient to doctor’s orders, and not prone to questioning care. As a result of both their age and their perceptions of health care professionals, there was an unconditional trust and an expectation of ‘good care’:

> And I think a lot of them, a lot of older people, have been so healthy all their life and all of a sudden they get ill and never visited their GP before and they are so, and find it a privilege that they trust you so much. It is a great privilege to have

> that, they trust you so much with everything. And there is a sense of respect and everything there from them. (CNS Fenton, lung clinical nurse specialist)

Rather than promoting patient involvement, trust in all medical decisions was often given to the doctor:

> Older patients commonly say, 'If you say so, doctor. That is fine; I'll just do that.' It is very difficult if you are into trying to empower people to make their own decisions … they're still in that era of, the doctor says … the healthcare professional is very much in control … it has to be a joint partnership. They kind of put you on a pedestal. (Occupational Therapist Clarke, dissemination focus group)

Age seemed to be a significant factor in explaining why this particular group of patients did not seek further help, as they tended not to ask for information and normalized their illness to their age. Professionals were almost encouraged to be paternalistic as a result of how older people looked up to them. However, professionals often became paternalistic, making decisions which were not always shared with the patients. Older patients found the medical language to be difficult, which further complicated their understanding. The following field note reinforces this:

> While professionals conveyed paternalism, patients sometimes did not understand the medical jargon thus from a societal and individual belief care was not truly collaborative (field note, February 2007).

There was less of a partnership in decision-making due to professionals protecting them because they were perceived as being old and being paternalistic. However, findings demonstrated that not all participants accepted information without questioning. Some participants wanted more partnership in their care, as the following section highlights.

Active participation

Professionals tended to find opportunities during ward rounds, or while giving direct care, to talk to patients about issues relating to their illness. Some situations were less opportunistic than others, depending on who patients were talking to. Patients tended to look to nurses for information and appeared to trust them within the therapeutic relationship invoked through care giving. Mary wanted an equal partnership and would ask the doctor about her results:

> I just chose to be an active participant … in my care rather than a passive patient and I have to say that sometimes that can get up the noses of medical people because although they pay lip service to you, being an active participant, even occasionally you can get from nurses when, 'Oh that's a good result from my blood pressure', it's almost as though interpreting blood pressure is our job, not yours. I suppose it's very difficult. (Mary, breast cancer with metastases, specialist ward)

Some explanations for this autonomy and self-determination could have been due to the patients' education. Mary had been an ex-headmistress and was also involved in the Trust Board as an expert patient, so she was used to talking with professionals. This is important, as findings revealed that participants who were more active in their care were better educated and looked to professionals to give more information rather than just accepting what they were told. One of the patients interviewed, Jinty, had been a nurse on the ward in which she was a patient. This added insight caused her some confusion, as she dealt with her identity as a patient as well as a nurse. Her 'inside knowledge' of ward processes and some staff members made her feel vulnerable, since she felt that standards of communication did not match up with the level of care she, herself, had provided when she was a nurse:

> I wouldn't have done that when I was a nurse, that isn't good practice (Jinty, breast cancer, specialist ward)

Part of her trusting others was based on being reflexive, looking to her past experiences, which informed her future expectations. It was also of interest that patients who wanted to be involved more in their care were in the specialist ward. This could have been due to the familiarity with staff members and the longevity of their illness. This section has discussed the challenges of power balance, withdrawing information and lack of communication. Trust appeared to be either active, as the above section has implied, or passive. Part of being passive appeared to be due to a lack of understanding.

Misunderstanding

As previously discussed, information and support in both wards was complex from a geographical standpoint, due to patients being located in a general hospital with limited access to specialists. From an individual perspective, older people also had functional deficits such as being bed-bound or hard of hearing, which limited their understanding of advice from specialists. Some patients did not ask questions (although they might not have had or heard questions). Others did not understand what professionals said, some stating that it was like a foreign language or 'mumbo jumbo':

> I sometimes have to get a dictionary out as I do not understand what the doctors say – it's like 'mumbo jumbo'. (Graham, liver metastases, unknown primary, specialist ward)

Graham was relating to the nature of how things are said and that information should be termed in an understandable way. This reference was made in relation to how doctors speak. Graham also had a dictionary by his bedside to make sense of information

following consultations. In addition, two of the patients had hearing problems and were cared for in bays, which also made comprehension difficult due to environmental ward noise (discussions, ward rounds, meal and visiting times). A lack of understanding was caused by medical jargon, hearing problems and the level of busyness in which patient care was delivered.

The complex nature of trust in this study relates to the cultural background of being older, thinking doctors know best and accepting the care with little information. Part of this lack of information is also due to the acuteness of the illness. Patients are often too ill to concentrate. In some cases, the care environment can hinder individualized care. Thus, the pattern of findings relates to the cultural and individual embodiment of illness from both a societal and individual discourse.

This section has discussed clinical and psychosocial factors surrounding trust for patients and professionals in the study. While trust is an important theme and central to accepting care, how the care is managed, especially the transition to palliative care in the two ward settings is significant, given that palliative care demands quick referral to ensure the right destination for end of life. To facilitate appropriate care, trust through familiarity further facilitated patients' needs.

Familiarity

Familiarity was noted as important in various ways: professionals' time on the ward, past experiences with other members of the family. The professional participants on both wards who were interviewed had worked on the same ward between 5 and 13 years. Several professionals on the specialist ward described it as being 'like a family' or a 'place

like home'. This indicated that they had an emotional attachment to the ward. This was most prevalent with the nursing staff, who spent the most time on the ward, coordinating care and interacting with patients over time.

This familiarity was noted by patients when they were admitted, as they sometimes knew staff that had cared for their family members (two patients were familiar with the ward: one male patient's wife had died in the same ward and another patient was a nurse on the ward).

> I know this ward, as my wife was treated here for breast cancer. (Andrew, medical ward)

> I worked here as a nurse so I am used to the ways things are done … this is why [they] should know not to say that as a nurse. (Jinty, breast cancer, specialist ward)

The familiarity of the ward was beneficial for patients from a social perspective, in knowing 'how things are done' or being used to the same professionals. Professionals related familiarity to their frequent treatment of cancer and having a close acquaintance with their patients. The chaplain who visited both the wards recounted his experience of familiarity. He stated that he knew patients' families through his role outside the hospital and that older patients were comforted when seeing him in the hospital:

> There is a kind of familiar, manageable scale, characteristic to the *hospital*. It is part of a larger organization now, but nonetheless manages to retain something of this geographical identity. And, you know, when folk are here they know where we are coming from, their home and family ties and think that is value. You can do the same with a city but it is a little more remote… (Chaplain Forbes).

Additionally, a pharmacist said that some patients knew her father, who was also a pharmacist in the local area. Familiarity is helpful in a temporal and past-experience sense. It was also noted that therapeutic relationships were generated with staff through both familiarity and social interaction, especially in the specialist ward. Thus, from a patient's perspective, familiarity was related to the past, providing a way to make sense of the future. Professionals also liked the familiarity of returning patients, which encouraged more of a social bond and developed a further understanding of patients' needs. While the social familiarity of patients was important, there was also a professional benefit in the 'notion of sameness' from a perspective of the disease process.

Place of care and 'notion of sameness'

Professionals faced a challenge in negotiating a care package to suit patients' needs during the short admission time of an acute care environment.

> Some of them know they are coming to the end … it's finding another place … some want to stay here but we can't. (Staff Nurse Percival, medical ward, focus group two)

There were patients from the medical ward who were all going to another place for their care. Ruth was to be discharged with the Macmillan palliative care service (community). Janet was to be admitted to the hospice nearby. Bertie and Graham were going to a community hospital (they could not get into the hospice). Bertie did not want to go to another ward:

> I wanted them to give me a jag[58] here but they said no … I don't want to go but I cannot stay … I sing about the cats and dogs; that helps. (Bertie, Liver metastases, unknown primary)

In my field notes, I reflected on the fact that Bertie had no family. He enjoyed the company of the ward, and I felt he would have benefited from staying in the ward. They were also investigating whether he had brain metastases and I wondered if the next place of care would be equipped to care for him, given the need for cancer and palliative care support.

In comparison, the focus of the specialist ward was determined on dealing with the needs of the patient at the time, with longer-term goals which encompassed future admissions. The supportive aspects of care related to future chemotherapy and a self-admission policy, which encouraged self-management. This was reinforced as professionals presumed that patients would return to the same ward if they needed further treatment or had an acute episode within their illness. The notion of repeated admissions to the specialist ward meant there was more of a sense of continuity and caring.

> I never am neglected here, ever, as I am always coming back. Here they see you as a person. (Mary, breast cancer, specialist ward)

The specialty of the ward being 'all the same' – solely oncology and haematology – allowed professionals to have a familiarity with the illness.

> Because it is a specialist area, everybody that comes in gets a different type of care than just being in a general ward, because that is what we are focused on,

[58] Jag is an informal word meaning injection.

> cancer care. We are aware of the fact, especially patients coming in with coma, whereas they have other things going on which we deal with, but primarily it's about the cancer care. But you cannot take that away from someone; you cannot split somebody down the middle and leave all their medical problems at home and bring just the cancer. We are aware that we deal with it as a whole, but very more focused on cancer care. (Staff Nurse Formage, specialist ward)

The above quotation also highlights that the professionals were more focused on cancer care than on gerontology care. Familiarity with the disease and the person helped the patient experience, but sometimes the focus of care conflicted with patients' expectations (this was the case on the medical ward).

While the focus of care influenced the familiarity with professionals, the cancer journey was also an important aspect in defining care for patients. Greater familiarity with others often depended on the length of the cancer journey and multimorbidity. The stages of the cancer journey will be discussed further below.

Stages of the cancer journey[59]

Patients had various diagnoses: breast cancer (2), prostate cancer (2), liver metastases with unknown primary (2), lung cancer (2), hairy cell leukaemia (1) and colorectal cancer (1).

See table below which shows how the patient sample differed within each of the wards:

[59] Typical illness trajectories have been described for patients with progressive chronic illness such as cancer (Murray et al., 2005).

Specialist ward (diagnosis)	Medical ward (diagnosis)
Breast (2) Unknown primary (1) Hairy cell leukaemia (1) Prostate (1)	Lung (2) Colorectal (1) Prostate (1) Unknown (1)

It was noted that in the specialist ward there were more investigations being carried out. In the specialist ward, apart from David, who had hairy cell leukaemia, patients were in the palliative care stage of the cancer journey. However, despite their stage of the disease they were still undergoing more treatment such as Graham who was being offered interstitial 5-fluorouracil for his liver metastases and Jinty who was still being offered chemotherapy. However, some patients had suffered from their illness for over four years (Jinty and Mary).

In contrast, in the medical ward care was more supportive, managing breathlessness and pain. It was also noted that patients, such as Ruth and Janet, had been diagnosed within the past year. They had already had radiotherapy but no further treatment was being offered. Thus the management of the illness was different on each of the wards due to the focus of care. Patients also seemed to acknowledge that the focus of care within each ward was important in giving options:

> R1: They just wanted to get to [*the haematology*] ward *. Maybe it is because they know if they are coming here then they are going to be having treatment, whereas if they are not, then they are not.

> R2: That's right. We don't look after every cancer patient, we just look after the ones, usually the haematology ones or the ones that are undergoing treatment.

> R3: It is actually quite interesting, because a couple of years back we had a patient who wasn't a haematology patient; she came here because she had been a senior nurse with another type of cancer but once her treatment was deemed 'end-of-road' she really didn't want to not be coming back here. And I think a lot of that was psychological, acceptance of the fact that there is no more treatment here. We're not going to be giving you any more treatment and she found it very difficult to hear. She wanted to come back here. (Dissemination focus group three, specialist ward)

This dialogue within a staff dissemination focus group established that patients seemed to like attending the specialist ward, due to the fact they administered chemotherapy. The focus of care was interventionist in approach and appeared to foster positivity in patients that there were more options.

> I like being in this ward, I know the staff … if nothing works they'll always try something else…. They know what I want. (Mary, breast disease, specialist ward)

The specialist ward not only provided comfort for patients due to treatment intent but also fostered optimism within professionals.

> I have been in the Haematology Unit for six years and I see changes, the massive changes that have happened even just in the time I've been here and the huge leaps. The non-toxic side of the treatment now, is massive.... In years to come, I'll look back and say we used to give them chemotherapy, remember what I did. (Staff Nurse Kew, medical ward)

> Say for instance lung cancer, which is the medical ward…. Patients on ward * usually do not get active treatment, meaning they are either branded, diagnosed or deemed not fit enough for chemotherapy; therefore, you are dealing with a more hopeless bunch of patients, if you like. (Staff Nurse Gamlin, specialist ward)

The issue of giving options through chemotherapy was also a challenge for some professionals. Despite some professionals telling the truth, decisions were changed without discussion between professionals.

The pharmacist conveyed the notion that all patients who are not in the specialist ward have an impending death sentence and are not fit enough for treatment, thus highlighting again the focus of care being dominant in care delivery. However, despite the progress made in giving chemotherapy with fewer side effects, older people were not always given chemotherapy, leaving professionals with the tension of not being able to offer treatment:

> I think because haematology relies on trials quite a bit, and a lot of them aren't entered into trials because of their age and they aren't fit enough. Sometimes they feel a bit cheated because of that. (Staff Nurse Kew, specialist ward)

Thus, being older may lead to patients not receiving treatment and perhaps being perceived as less worthy because of their age.

It appeared that on the medical ward there was more of a focus on rehabilitation in preparation for their next place of care. There appeared more access to allied health care professionals such as occupational therapists and physiotherapists, whereas on the specialist ward there was more access to oncology specialists and clinical nurse specialists in cancer care. In sum, the focus of care, whether active, supportive or palliative, appeared to affect the services which were available to patients.

Multimorbidity

This section will discuss multimorbidity of patients. A sampling grid was developed that highlighted the 'symptom clusters'[60] and multimorbidity. See Table 9, which represents the complexity of patients' symptoms[61] and multimorbidity, which gives insight into their supportive care needs. Being older affected their self-care abilities, as some had multimorbidity. Knowing how to manage the older person can be complex, given their understanding of their illness, past illnesses and multimorbidity:

> You get people in their seventies who are coming in here with a cancer diagnosis who have multiple comorbidities, so it is very difficult to generalize, as there are so many aspects to their care. Maybe what it could be is something like some kind of person who could specialize in tying it all together (Staff Nurse Kew, specialist ward).

Participants all had complex symptoms such as breathlessness and pain. It was important to discuss the patients' symptoms, as they created a picture of their 'total pain'[62]. See Appendix L.

It appeared that care pertained to two domains: age-related physiological decline[63], and

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[60] Symptom clusters are defined as three or more concurrent symptoms that are related to each other (Miaskowski et al., 2004).

[61] Management of pain and other symptoms and providing psychological, social and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments (WHO, 2006).

[62] Dame Cicely Saunders defined the concept of total pain as the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles (Richmond, 2005).

[63] Ageing is a complex process composed of several features: 1) an exponential increase in mortality with age; 2) physiological changes that typically lead to a functional decline with age; 3) increased susceptibility to certain diseases with age. Ageing as a progressive deterioration of physiological function, an intrinsic age-related process of loss of viability and increase in vulnerability (Phillips et al., 2010).

other cancer- and treatment-related symptoms. All participants had multiple symptoms indicating the complex clinical picture of being older and living with cancer. Six out of the ten patients reported multimorbidity such as past cardiac problems, and one had a previous cancer:

> Hmm, my angina, unstable angina and heart attack: these are all things that, I suppose there's difficulty with them too. I just take it as it comes (Andrew, prostate cancer, medical ward)

> Of all the things I've had, I suppose my heart could go at any time. So it's not much difference; it's still the same. My hips and my knees are just things they couldn't fix either. (Alexander, prostate cancer medical ward)

It appeared multimorbidity needed an evaluation of chemotherapy treatment and overall consideration of intent of treatment in a *holistic* sense. David needed a chemotherapy drug which was cardiotoxic (Adriamycin) but, due to his existing cardiac status, he had to have arsenic (a clinical trial drug). On experiencing this he said:

> … the effect of having arsenic was worse than having leukaemia and my heart attack put together. (David, leukaemia, specialist ward)

Disease-related symptoms and other chronic illnesses affected patients' functional ability:

> The nurses used to walk with me every hour, but I am now so tired I cannot do that. I need my oxygen all the time. (Ruth, lung cancer, medical ward)

Findings in all transcripts indicate that patients in both wards experience challenges in receiving appropriate care and maintaining independence. The medical ward had more dependant patients due to the symptoms which made them bed bound (4 out of 5) and isolated. On the specialist ward because patients were more able and because there was

more opportunity to develop a therapeutic culture, patients could express their needs. Due to the focus of care on the specialist ward there were also more options for treatment. However, both wards did not have a systematic process for assessment and there were challenges in decision making. The need for holistic decision making considering multimorbidity and the needs of frail patients would have supported informed decision making and promoted self-care. The need for shared decision making will be discussed in the next section.

Independence versus dependence

Patients were compromised due to symptoms. Socially, staying in a side room with reduced interaction and mobility outside of their bed area reinforced isolation and functional dependence. This quotation is an example of the tension of clinical dependency:

> … Older people come and become completely dependent on you, a) because they have never come across it before, b) because they cannot actually give themselves their treatment and they need to be here for it…. But you make them wholly dependent on you. 'You have to stay in that room, we'll bring your dinner to you, we'll bring your towels to you, we'll make your bed and we'll, we'll, we'll.' And then you've got to try and reverse that to give them that independence back again. (Staff Nurse Jones, specialist ward)

On reflection, it seems that professionals on both wards were challenged by the dependent nature (physical and emotional) of older people with cancer due to the perception of their diagnosis.

> Because sometimes, older people will get difficult when they want everything done for them, but I think the nurses do give them that chance: 'I think you can do that yourself.' But possibly when we do give them bad news like, 'You've got cancer' we'll maybe feel the whole empathy, the sympathy coming on board

> and we might tend to do things for them in that instance because they've had bad news; we feel sorry for them. (Staff Nurse Jeana, medical ward, focus group)

Professionals may perceive older patients as not being proactive in their care. The transition to palliative care was somewhat blurred, as independence is seen as a goal within the culture of rehabilitation. This inappropriate philosophy of care lessens the recognition that entering palliative care should mean focusing on self-care within a patient's functional ability. Professional roles permit certain aspects of negotiation with patients better than others. Better understanding of a patient's diagnosis combined with recognition of their potential frailty due to being older would give a better indication of their needs.

> They lose independence. I don't know if any of that comes from us and how we treat them, but I certainly have noticed that is the way that they respond to news. (Staff Nurse Scrimingeour, medical ward)

Treatment-related factors such as fatigue and longer term effects such as neuropathy demonstrate the complexity of symptoms related to cancer care. One of the participants (Mary) had tinnitus as a result of the carboplatin[64].

It was unclear if they would go to their next place of care with fewer symptoms. This is significant, as it would have further distinguished some professional challenges in the transition to palliative care:

> We have to move them on so we cannot spend time looking at everything ... it feels like a 'rushed job' at times. (Staff nurse Jeana, medical ward)

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[64] Carboplatin is one of a series of platinum analogue drugs used in cancer therapy.

Findings demonstrated that with all patients there was an interplay of symptoms and multimorbidity. The focus of care affected how patients were managed by professionals. While patients talked about their multimorbidity in relation to their past and current events. This current study indicated that 'symptom clusters'[65] are evident in all the patients, but not all symptoms were assessed and so reinforced dependence. Professionals on both wards needed to assess symptoms and multimorbidity for each patient so that there could be a timely referral. The assessment of symptoms was needed as patients had symptoms which were not obvious like fatigue and or appeared depressed due their situation and uncertainty. It was clear that having cancer alone with or without extensive impairments and physical changes, its prognosis had a bearing on attitude in that if patients where having treatment then there was more expectation for recovery. This was also the case in where the patient was cared for. However, the need for timely referral to specialists was equally important as the identification of symptoms. The need for timely referral to specialists will be discussed in the next section.

Referrals to specialists

This section will discuss patient and professional perspectives in relation to referral to the lung CNS and the palliative care services. Working with other clinical nurse specialists[66] facilitated decision-making, but the process of when to involve others was often unclear,

[65] Symptom clusters have been defined as 'two or more concurrent symptoms that are related to one another and independent of other symptoms or symptom clusters' (Barsevick, 2007).

[66] The definition of a specialist nurse in cancer and palliative care is: Clinical Nurse Specialists in cancer care can be described as registered nurses, who have graduate level nursing preparation and who would usually be expected to be prepared at the Master's level. They are clinical experts in evidence-based nursing practice within a specialty area. The specialty may be focused on a population (e.g. young people), type of care (e.g. palliative care), type of problem (e.g. lymphoedema), type of treatment (e.g. chemotherapy) or tumour type (e.g. lung cancer) (Royal College of Nursing, 2002a).

as there was no written protocol for referral[67]. Lung Clinical Nurse Specialist Fenton remarked on the challenges for continuity of care between the service she provided and the acute setting:

> But you don't want to step on their toes either because of specialist and general nursing … they are not always quick at coming and letting us know the patients are in and we find out by default about three or four days down the line. And the relative phones and says 'Oh my mum is in such and such and I've not seen you.' (Specialist Lung CNS Fenton)

The timely referral for general or specialist palliative care seemed to be blurred at times, due to the priority in the medical ward of discharging patients on to the next place of care. However, the medical ward had many professionals to call upon for guidance in relation to rehabilitation:

> I think it is quite helpful to think of us as a base to get here first information and to all the nurses on the ward, the doctors and the consultants. But they don't need to be here all the time…. This is a great starting point and the way this ward works may be not like the other wards but there is quite a lot of outpatient activity on this ward as well as inpatient activity. (Staff Nurse Duke, medical ward, focus group 2)

The medical ward could be described as a place which assessed patients' next place of care rather than caring for them during the palliative care stage. The transitional stage was often complex for professionals dealing with end of life issues. As noted previously, there appeared to be a fragmented system, due to being in a cancer unit when there is less access

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[67] Key nursing documents make explicit the need for specific support from specialist nurses in cancer care, especially in generic ward settings (when the specialty is not cancer). However, in a cancer unit, referrals to CNS in lung, breast or specialist care can be lacking due to funding and, as a result, clinical areas are under-resourced (Royal College of Nursing, 2002b).

to specialists than in a cancer centre. This resulted in some patients not seeing their consultant when in the cancer unit. As Staff Nurse Kew commented:

> The hard part of the oncology side is you do not follow them up. We are only a mechanism to give the treatment … because the consultants are not on side with us … this makes it difficult when we feel treatment should be stopped. (Staff Nurse Kew, specialist ward)

In the specialist ward, care was mostly provided by the nurses, who were experienced and educated in the giving of chemotherapy, with some even having post-registration education or a degree in cancer and/or palliative care. However, the tensions involved stopping treatment; thus moving to a palliative care intent made the referral pattern to the palliative care team a challenge. Symptom management was also an issue for all patients, without exception. Many patients in this study appeared to experience cancer as a biographical disruption, in that it represented a threat to their lives in both a clinical and a social sense. The way patients experienced symptoms is discussed below.

Experiencing symptoms

In this section, findings related to the experience of symptoms will be discussed, contrasting patient and professional experiences in the medical and specialist ward. Patients' clinical experience of pain, breathlessness and side effects of chemotherapy treatment often disrupted their previous assumptions relating to their quality of life. Their diagnosis brought functional and chronic changes to their lives, such as breathlessness due to lung cancer, or bone pain due to metastatic spread.

Mary, Janet, Graham (all specialist) and Bertie, Alex, Jan, Andrew[68] (medical) all talked about their symptoms, which were not all resolved. It was also clear that their *'total pain'* was complex, from multimorbidity, loss and anxiety. For all patient participants in the study, their symptoms caused disruption to daily routines and interfered with their activities of living[69]. Patients with lung cancer (Ruth and Janet, medical ward) were breathless and bed-bound, needing total assistance with activities of living. Bertie and Archie were also bed-bound due to metastatic disease and spinal cord compression. David was less incapacitated, but endured side-effects from his chemotherapy, such as myelosuppression[70]. Jessie, Mary and Andrew endured pain from breast and prostate cancer. Pain was the most reported symptom mentioned by patients and professionals. Pain management appeared to be a problem, due to various myths believed by patients, such as that having cancer equated to experiencing pain. Being older seemed to act as a barrier in communicating symptoms, and having pain seemed to be viewed as normal in old age. Older patients were also perceived as less deserving of specialist care. From a professional perspective, older patients tended not to make a fuss, which further augmented the risk of inattention to symptoms that they might not have disclosed:

> And they are not complainers and moaning for the sake of moaning. And they don't like to complain. If you go round and speak to them and ask 'Why did you not say? We can't tell if you are in pain, or if you need something; if you don't tell us we don't always know.' They say, 'We don't like complaining.' And that is the older generation. (Staff Nurse Jenkins, medical ward)

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[68] Andrew had a pain chart at the end of his bed, but other patients who were in pain did not.

[69] 'Activities of living' is a term used in health care that refers to self-care activities such as personal hygiene and grooming.

[70] Myelosuppression is a side effect from chemotherapy that occurs when the bone marrow is suppressed, resulting in a poor ability to fight infection.

Field notes from one visit to the medical ward recorded a nurse commenting on poor pain management on the ward. It appeared that patients tended to have pain that was unresolved; this was noted with a few patients on both wards. Due to the nature of some patients' disease progression, bone pain was a common symptom from their primary cancer site[71]. Some patients reported that their pain was unresolved, but saw this as part of having a cancer diagnosis, perceiving their illness and pain as expected, in a reinforcement of their past beliefs and associations with cancer. Transcripts from participants described how patients lived with the pain. Some used coping strategies (see below), while some felt helpless but remained controlled, making plans for a good death by deciding to end all treatment. This is a quotation from Alexander about living with his pain:

> The pain I could suffer … I know I've got pain there, I could suffer that no bother, it's when it gets to the point when it is worse and during the night, oh, it was rough. I don't know when I was last in bed. I just sit in this chair and let the world go by; the bed's no use to me. (Alexander, prostate cancer, medical ward)

Some patients adjusted their daily activities in order to minimize the symptoms without interventions from professionals, thus showing inner control. Three examples of this are as follows: firstly, Andrew sat up in the chair throughout the night, accepting that lying down was not an option; secondly, Bertie accepted the pain he would experience when being turned in bed, in return for the prevention of his skin breaking down; thirdly, Jinty was not able to wash herself with two hands due to the pain from her lymphoedema, so she washed with one hand (the nurse said she did not help Jinty as she thought she really could wash herself).

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[71] Primary cancer site refers to the site from which the cancer had initially grown.

> She would not help and said I could wash, but I couldn't. I reported her to the charge nurse. Surely she could see my arm is 'dead'. (Jinty, breast cancer, specialist ward)

Against adversity, Jinty still tried to wash herself with one arm, despite the fact that she had lymphoedema. Pain seemed the most prevalent problem, especially in the medical ward.

Fatigue was also a common symptom in this study, as patients could not sleep due to pain, being in a hospital environment and worrying about their future. It was clear that patients' pain was not being managed, but how patients self-managed the pain related to both their perceptions of cancer and their resilience. This will be discussed more in the next chapter.

Breathlessness was physically and emotionally overwhelming for two patients in the study. Breathlessness affected their ability to carry out activities of living and affected their quality of life:

> … If I could get this breathing, because I have to sleep with this [oxygen] on at night. The only time I don't have it on is if I am just going to the toilet for a wash; they've got to give me the oxygen. (Janet, lung disease, medical ward)

> They were telling me, all the rest of my days I would have difficulty in breathing so 'Audrey [daughter], if you do not give me any of these things [oxygen cylinders] that last for 9 hours I'll be stuck in the house all the time.' (Ruth, lung disease, medical ward)

The physical manifestations of their cancer influenced how patients coped with activities of living such as walking unaided or going to the front of the hospital for some air. Despite the incapacitating symptoms, Janet and Ruth looked to desires and expectations to help them cope, asking for support from professionals to help them deal with their symptoms.

However, it appeared that most patients, particularly those in the medical ward, lived with the uncertainty of not knowing what their personalized care plan[72] would be.

Most of the patients in the sample were incapacitated due to their illness and therefore had to adapt to their existing physical state. In all the patient sample, symptoms were complex due to multimorbidity (all), receiving chemotherapy-past (seven), present (three), and resultant disease-related issues such as cachexia (two of the patients in the sample had cachexia [medical ward]) or spinal cord compression (two of the patients [medical ward]). While patients lived with their symptoms, they also looked to their life and the impact of their symptoms on their activities of living. Differences in both wards were related to the impact of symptoms and the supportive care required. The trajectory of the patient journey was shorter in the medical ward than the specialist. However both wards had a lack of assessment which made symptoms prevail. This was also due to the lack of referral to specialists. There was a lack of referral to cancer services on the medical ward and a lack of referral to rehabilitation services on the specialist ward.

However, *professionals* discussed the management of symptoms in different ways, and, depending on the ward they worked in, made sense of patients' needs in relation to the *'master specialty'* of the ward. The specialist ward had more of an interventionist stance, giving patients single-dose chemotherapy for symptoms such as pain or IV antibiotics for

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[72] Personalized care planning aims to put people on an equal footing with health and social care professionals, moving away from "doing to" to "doing with". A care planning consultation should feel like the "meeting of two experts" – the patient/client and their clinical carer (Morton and Morgan, 2009).

Many benefits can be gained from personalized care planning. International evidence shows best outcomes are achieved when there are: systematic proactive services; people engaged in their own care; and healthcare professionals and people with long-term conditions working in partnership (Wagner et al., 1996).

infections. As Staff Nurse Kew said:

> But this older patient was really ill and she needed multiple transfusions, needed chemotherapy ASAP, and with hindsight she probably should have been much better hydrated, but she was also anaemic when she came in so … and get her haemoglobin checked out and get her some chemotherapy and the kidneys probably didn't cope well…. (Staff Nurse Kew, specialist ward)

The specialist ward managed symptoms with treatment such as antibiotics and further assessment, while in the medical ward management of symptoms was more long term. Patients in the medical ward were commonly treated for breathlessness relating to non-malignant and malignant diseases. The length of stay was shorter but was equally complex in assessment as the specialist ward. As Staff Nurse Scrimingeour said:

> … There is a man today that has just been diagnosed with cancer. He is the palliative care patient. You get the ones who cannot be treated … but symptoms can be treated. (Staff Nurse Scrimingeour, medical ward)

The context of being older also means that staff looked to home care to ensure that patients had support at home. This did not just provide functional support, but also emotional support by helping patients to understand their diagnosis. Staff Nurse Jenkins also stated that because older people do not always understand information due to their reduced cognitive ability, they might need extra support. This lack of ability to manage information has also been related to being older; perceiving that it is the end of their life and they can often be less interested in the choices and options.

> Oh I don't mind, no darling, not if they leave me in peace because they try and make me walk. I have done a little bit of walking, but it is hard work. But they are very kind people. I just tell them to leave me alone, because I sleep a lot. I can't walk I just want to go now. (Bertie, unknown primary, medical ward)

However, some professionals spoke of not having a lot of time to be able to be with patients, and this frustrated the majority of participants interviewed in the medical ward. Professionals enjoyed dealing with their symptoms and giving physical care which enabled them to listen to patients:

> Just to sit and spend time with the older patients … you can listen to them and they can ask you if they have any concerns. Or explain a wee bit more about the care they could get. (Staff Nurse Jones, medical ward)

Professionals in both wards were aware of the need to give physical care, which was valuable in assessing patients' individual needs.

> But even they [patients] say there's no treatment for the elderly, but if they've got severe pain that's not controlled you can get some radiotherapy that will help that pain and make you feel a bit better. So there is always a wee bit of positivity there that you can give them. And it's not, chuck you behind the door and shoot you, there is always something we can do to make it easier for them. (Focus group two, Staff Nurse Percival, medical ward).

In both the specialist ward and medical ward, patient needs were complex from both a psychosocial and symptom management perspective. Professionals used the focus of care, whether for acute or palliative care, to inform clinical management. Being professionally competent to manage symptoms of older people with cancer was something that came through education and experience.

Education and experience

Both of the wards had a high commitment to teaching and learning, as well as access to a practice placement facilitator who ensured that students had an adequate learning environment. There were, however, some differences in focus: the medical ward had an

emphasis on teaching respiratory care, whereas the specialist ward had an interest in developing skills in haematological care. Neither ward aimed for specific educational outcomes in either gerontology or geriatric medicine, but some professionals in both wards had post-registration and postgraduate qualifications in cancer and palliative care.

In the medical ward, the charge nurse was studying for her Master's degree in respiratory care. She encouraged her staff to attend post-registration courses in respiratory medicine. Each of the wards had access to a practice placement facilitator who ensured that students had an adequate learning environment. Most staff on both wards had taken a mentorship course through the University of Dundee to make certain that an adequate learning environment was provided for students during their placement.

Most of the professionals in the medical ward were not specifically trained in cancer or palliative care, although two interviewed on the medical ward had taken a post-registration course in palliative care and one also had undertaken a post-registration course in cancer care and palliative care (degree level). They also had access to an NHS cancer care educator, who gave in-service sessions on cancer and palliative care issues on a regular monthly basis. Two of the nurses had undertaken a counselling course. The professionals on both wards had *no education* in gerontology. This is important, as understanding the older person is as vital for these patients' care as understanding cancer and subsequent patient needs. Reflecting on the ward as a halfway house, the fact that professionals did not have education in gerontology may have meant that their care was not truly informed as to the patients' needs.

Most professionals' accounts in this current study discussed the need for education and

how it was helpful in the management of patients, not only in clinical ways, but also in providing psychosocial support to allay professional myths relating to cancer and old age. One example of this was teaching professionals how to reduce patients' fear of cancer so that it was not such a 'scary word':

> I think I understand patients a bit better and I think cancer is such a big word … well, it is not a big word, but it is quite a scary word. … My God, cancer – you are going to die and that's the end of it. But it is not until you actually sit and you read about it and go on courses and everything (my degree was about that) that you realize that you might have cancer but a lot of patients live with cancer. (Staff Nurse Jenkins, medical ward)

As stated above, the specialist ward had more of an educational focus on haematological diseases and the delivery of cytotoxic chemotherapy. All staff had taken a skill-based chemotherapy course at a cancer centre. Most of the staff had also attended a postgraduate course in haematology, but not specifically in cancer care. However, two staff members were enrolled in a Master's programme in cancer care.

In relation to key roles in facilitating and delivering care, it was clear that nurses were perceived as being patients' advocates, facilitating both their physical and psychosocial care. However, enhanced education and experience in dealing with acute symptoms of some cancer patients was more prevalent among staff on the specialist ward.

> … you get used to seeing how patients develop in relation to the diagnosis of their symptoms, because we are used to it, and I suppose it is because we see it all the time. So, it is easier. It would be much harder for a general ward to focus on a haematology issue because they are thinking of so many other things like the symptoms of other patients ... for our patients we know sepsis. (Staff Nurse Knowles, focus group 1)

Nurses within a focus group gave examples of how they saw themselves as expert in

haematology care, as opposed to staff in general wards, due to the belief that having the same type of patient gives added experience and greater knowledge.

> We are used to dealing with patients with cancer or haematology illnesses. We see patients with cancer all the time. We are well used to this in comparison to other wards where seeing patients who have cancer may be very scary. (Staff Nurse Krise, specialist ward)

The clinical 'notion of sameness' and familiarity with cancer patients benefited nurses dealing with clinical and psychosocial interventions in the specialist ward. As demonstrated by the findings of the current study, familiarity with patients and knowledge of the cancer process are essential in promoting a therapeutic relationship. Also, the notion of sameness facilitated the application of education. Findings focused on the benefit of education, particularly in cancer and palliative care. However, there was no discussion from any professionals about educational needs from a 'gero-oncology' perspective. This has been recognized in other studies. Insight into the ageing process and the transition to palliative care is equally important as recognizing the disease process. Another aspect within these complex symptoms is the point at which palliation is shown to begin.

The transition to palliative care

When a person has advanced cancer, adopting a palliative approach to care would signal the recognition of inability to cure the cancer, with the successive decision to both treat the symptoms of the cancer and give the patient support in preparation for dying. It could be argued that older people with a diagnosis of advanced cancer are at the 'end of their life' and thus the main need in their care is preparation for dying. However, without a clear decision to change the emphasis of care, symptoms could be at risk of being left untreated.

There were challenges in both wards in treating patients with palliative care intent, but for different reasons. In the medical ward, patients were in the palliative care stages, but the ward's philosophy of getting patients to the next place of care made ongoing assessment difficult. The assessment should be not just clinical but holistic, and looks at a patient's expectations and wishes:

> We can never get to know the patients, as they may go the hospice or we may never see them again…. (Staff Nurse White, medical ward)

In the specialist ward, the care was mostly treatment-led, and deciding that patients needed palliative care proved difficult:

> It is true … here we joke about why patients have screws on their coffin, as it stops oncologists giving them chemotherapy. (Staff Nurse Granger, focus group 1)

> We [nurses] are the ones who speak up for the patient and say, 'Now, enough is enough … the patient does not want this or that.' (Staff Nurse Jones, specialist ward)

These quotations indicate that there were professional challenges in moving to palliative care. As discussed earlier in the chapter, on the specialist ward the focus of care was usually to give chemotherapy rather than to move to the palliative care stages. There was reluctance on the part of the medical staff to refer patients to the palliative care team, especially on the specialist ward. This is exemplified in the quotation below:

> I think because the doctors are in control they don't want the palliative team, but it may be that they should. (Staff Nurse Scrimingeour, specialist ward)

The focus of professionals on the specialist ward was more interventionist in intent: they perceived palliative care as a consequence of failure and there was a reluctance to give up

active treatment for patients. This led me to consider when, and how, professionals discussed transitions relating to end of life care. While the focus was on cancer care, there was less willingness to discuss the palliative care needs of older patients.

Findings highlighted that care interventions were sometimes influenced by the rituals which governed care. The care environment rituals, such as ward rounds, seemed to hinder one-to-one discussions with patients and overall communication. A pharmacist gives an example of being on a 'doctor's round', and seeing this as a lost therapeutic opportunity to disclose information for *both* patient and health care professional:

> And there are a lot of times patients will say they are suffering from something and they've never told the doctors. The doctors have been on their rounds and the junior doctor rapidly writing down everything the consultant says and the patient doesn't ask the questions but they're supposed to [*conversation cut across with speech which signifies agreement*]. (Pharmacist Luca, dissemination focus group 3)

It could be argued that clinical routines such as ward rounds govern the context in which decision-making is made, thus restricting professionals from interacting with patients at these potentially important times. This finding suggests the importance of anticipating the various stages that patients may go through, but also highlights the different meanings that are attached to professional roles in relation to the power in decision-making during these stages. The challenges that professionals faced in decision making will be discussed in the next section.

Challenges in decision making

The dissemination focus groups provided an opportunity to tease out some of the tensions when dealing with complex issues in palliative care. Reflecting on the experience of being on the medical ward, a pharmacist discussed how medications are rationalized, though patients' consent is often lacking:

> I think there is a big focus on comfort as well with the pain control, and, from my point of view in pharmacy, for an elderly patient you might start to rationalize their medicines as well … and really just focus on their cancer care as opposed to their cardiac or general geriatric medicine. (Pharmacist Jones, specialist ward, dissemination focus group 1)

It is also noted that there was a decision to identify palliative care in relation to cancer, rather than to cardiac or general geriatric medicine. Professional accounts indicated that the medical work of doctors was in the shaping and management of 'illness trajectories'.

> And when you speak to medical staff you start to weigh up the pros and cons. Is this patient likely to die of a stroke before they die of the cancer? Then you have even more difficult conversations like, which is worse? These are things that are definitely considered. And generally at consultant level they are decided on borderline. (Pharmacist Verde, medical ward, dissemination focus group 2)

The pharmacist perceived the doctor to be in control of situations, rather than patients who may have wanted to also engage in medical decisions. The pharmacist empathized reflection about the psychological impact of medical decisions to change medicine, taken without patient partnership:

> I am sure that [changing the patient's drugs] will impact on the patient and the patient's family as well, because if they go home and they are on dramatically reduced medicines or dramatically increased medicines, that will definitely affect the way that they are feeling. It may affect their hope and their emotions;

> they may feel they are likely to get worse. I am sure that will affect their feelings. (Pharmacist Luca, medical ward, dissemination focus group 3)

She then discussed how she went back to the patient after the ward round. She reflected on her role, perceiving an advantage in being seen by older patients as socially less powerful than doctors, because it could generate more of a partnership in care. Staff Nurse Jenkins also reinforced the social aspects of her role:

> They're happier to speak to you as well and they'll ask you things like, 'I'm going for this tube thing down my throat.' And you're trying to say, 'What's that all about?' I get questions about procedures all the time … they feel it's easier to talk to us than the doctors, as they get all tongue-tied. (Staff Nurse Jenkins, medical ward)

Patients may not understand what is being said, as identified in the section 'Misunderstanding'. Nurses may be able to understand more about the person from listening to past events, which they may have talked about in previous admissions. In this current study, doctors on both wards were seen as giving information about the next stage of the cancer journey, while other professionals such as the pharmacists and nurses seemed to pave the way in making patient transitions easier, through 'being with' the patient, giving information and listening.

There appeared to be intra-professional conflict in relation to stopping treatment. Jinty was given further treatment, but this was not what she really wanted.

> I cannot go through this treatment any more I cannot go on with this … I have two wigs at home and I'm not bringing them in … they said I had to. I just gave up… (Jinty, breast cancer, specialist ward).

Similarly, Bertie wanted to end his life due to his uncontrollable pain:

> I cannot go on feeling this way … I said to the Doctor just shoot me … he said he cannot do that … I'm not long for this world… (Bertie, unknown primary, medical ward).

Patients' accounts demonstrate that they want to give up rather than carry on treatment. However, this caused inner challenges from professionals as they did want to stop treatment thus feeling that they were not doing their moral duty to patients.

> I get the feeling that some of the consultants feel that if they start something they must not stop, as it is like we've given up on them. We've given up and we don't want to give up; we don't want to lose. (Staff Nurse Granger, focus group one)

It was evident that entering the palliative care stages challenged professionals, in the sense that they found it hard to communicate difficult issues such as stopping treatments. The transition to palliative care was seen as 'losing the battle':

> I have worked in palliative care and I get quite upset at times. We had a lady who had dementia and they gave her chemo. She was a lovely lady and I didn't have issues with giving her chemo but I had issues with the form of consent. She's getting this really nasty drug that will give her really nasty side effects – lose her hair, sore mouth, diarrhoea and I had real issues and I said, 'Where's the issue of the form of consent here?' I know you have got to reduce the tumour because it is impinging on the lung, but she wasn't distressed in any way with the lymphoma, she was quite happy with her life. (Staff Nurse Verne, focus group one)

This quotation above caused a lot of discussion in the focus group and different professionals seemed to relate to one another's tensions around clinically doing the right thing for these patients who had complex needs. Patients on both wards were more open with their unmet needs in wanting to die:

> I cannot go on like this. I do not mind if they tell me this is the end, as I have had a good life and I cannot go on. (Bertie, unknown primary, medical ward)

On the medical ward, there was more of a readiness to reduce medicines, but with little discussion with the patient. An example of cutting down medicines is given below:

> You would do things that would limit how many blood tests you would do on a patient, because that is an uncomfortable procedure to give them, so you are not going to give them that procedure any more … when you speak to medical staff you start to weigh up the pros and cons. Is this patient likely to die of a stroke before they die of the cancer? The consultant will say quickly, 'I think you need to cut out this, we are quite happy to wind this up.' (Pharmacist Luca, dissemination focus group)

There also appeared to be power struggles in the specialist ward, as some doctors often did not want to give up, while nurses were more receptive to 'finding a balance' and exploring patients' needs. From focus group accounts, there appeared to be a hierarchy of power, with doctors being the most powerful, then nurses. This appeared to be reinforced when applied to caring for the older person. It appeared that in the palliative care stages, paternalism and a tendency to stereotype patients hindered a holistic assessment at times. Thus, societal beliefs, power differentials and systematic assessment resulted in difficulties regarding appropriate care for patients.

Discussion

This chapter has discussed care delivery in two ward settings (from both a ward perspective and a general hospital overview).

Findings in relation to the research questions

The main themes generated from the findings are related to the research questions in Table 11 below:

Table 11: Research questions and findings

How do these two settings (medical ward and specialist ward) shape:

Research questions	**Description of main findings**
• The older patients' and professionals' views on diagnosis and care delivery?	The cancer unit offered fewer options for radiotherapy but provided a familiarity for patients which were unique to the geographical setting. The familiarity for patients and professionals relating to repeated admissions and the notion of sameness enriched the therapeutic experience for both patients and professionals. The focus of care was not appropriate in both wards as was not totally appropriate for the older patient with cancer. Patients normalized their illness focusing on the social discourse of being old and their past experiences. Thus the impact of cancer was integrated into their past experiences. Familiarity and trust were concepts which enriched the experience for patients in the ward setting. This was evident more in the specialist setting than in the medical ward. Professionals normalized patients' illness when focusing on the social discourse of being older. The ward was 'a halfway house' in that patients were safe in a clinical and or emotional sense. In the medical ward the ward was safer in a clinical sense. In the specialist ward there were accounts of being clinically and emotionally safe as they knew professionals from before.

• The professional roles and responses to care delivery?	On both wards, nurses worked to an organizational discourse which informed how 'things were done'. There was a lack of assessment for the older patient with cancer on both wards (comorbidities and cancer related treatment). Care delivery was commonly underpinned by routine than systematic assessment or listening to patients' needs. This appeared more prevalent on the medical ward. While on the specialist ward there was more person-centred care due to familiarity of patients and a clinical understanding of cancer. Education enhanced the care delivery for cancer care but both wards did not have education in gerontology and cancer.
• The psychosocial experiences of older patients?	The business of the specialist ward resulted in care being more 'physical' than holistic. In the specialist ward it was more holistic due to familiarity of patients. Patients felt clinically and emotionally safe in different ways depending on the setting.
• The interpersonal dealings between patients and professionals?	Patients trusted professionals and respected their roles. The attributes of familiarity, repeated admissions and trust helped the therapeutic relationship and 'milieu' of the ward. This therapeutic 'milieu' was more prevalent in the specialist ward due to the trust and familiarity gained through time.

Overall, the specialty of *both* wards within the general hospital was not ideal for the older person with cancer. This was for several reasons: not all patients who were receiving supportive care returned to the same ward, so the chance of continuity was therefore lacking; if a cancer patient did not need chemotherapy, they did not necessarily get admitted to the specialist ward; the specialties of both wards did not truly embrace gerontology, geriatric medicine, oncology and palliative care. A field note stated:

> The management of care was arranged around the symptom rather than the importance of continuity. Thus the clinical needs were a priority instead of psychosocial care (field note, September 2011).

The two wards had hierarchical layers of interest: the focus was primarily on medical or cancer care rather than gerontology. Also, dealing with clinical issues and psychosocial needs appear to be competing interests, with the focus often on clinical issues, especially considering the high turnover of patients. The high turnover was of significance in reinforcing the older person with cancer, as a vulnerable group, not only because they are marginalized in society, but because in the hospital setting they may feel further isolation and fear when they are not known to the staff, or are coming in for acute admissions (especially on the medical ward).

In addition, the layers of the 'idio-culture' allow for competing values and categories, which create a contestation of priorities. Further pressure within the organizational culture can create a less-than-individualized approach. Findings in this study reinforced the organizational discourse as being oppressive and not conducive to person-centred care at times. A field note stated:

> Professionals in the medical ward were strained due to a culture of get the patient to the next place of care and saw the ward as transition than a place for continuity. The mechanistic nature of caring strained the process of person-centredness (field note, medical ward, August 2008).

The organizational discourse within the wards set parameters for 'how things are done'. However despite this being evident on both wards there were distinct differences in the therapeutic nature of both wards. The chaplain described the notion of trust as a 'deeper sense of knowing', 'reflecting on life which is there'. This finding brings into sharp focus

the importance of continuity for older people and the need to be near home and to know other professionals. The aspect of being familiar could empower older patients to feel a sense of belonging. As stated by Mary who was in the specialist ward (relating to professionals) ‘you are my family’. Having trust in professionals and perceiving that they were in the ‘hands of experts’ was also of importance. This could be argued as an essential aspect which supports older patients in a potentially ‘alienating’ environment. In addition this sense of continuity could also be emphasized as professionals know patients from prior admission and from their personal lives. Patients trusted professionals and perceived them at times as ‘all-knowing’ professionals and more of a partnership, where equal social engagement took place.

The notions of familiarity and sameness were applied both in an individual sense (knowing patients) and in the management of the same illness (cancer). Because the medical ward did not have the notions of familiarity and sameness, this could have affected the way patients experienced their care on that ward. A way to ensure ‘shared meaning’, was through a ‘notion of sameness’, but due to lack of assessment on being older and having cancer, care rested more on established values than assessment.

The conceptualization of the ‘ward as a halfway house’ was understood from either a clinical or emotional perspective, depending on the familiarity and connectedness generated between professionals and patients. This ‘in vivo’ code signified the clinical and emotional aspects of hospitalization. While patients felt safe at being in hospital they also wanted to be home. The ward as a halfway house also signified the ‘holding bay’ between the next place of care. Continuity, being close to others, familiarity of face and an emotional ‘notion of sameness’ were all factors that helped patients feel it was a safe place.

In this study, different caretaker roles provided diverse aspects of a therapeutic relationship, whether professionals were dealing with patients from a clinical stance or were more focused on their psychosocial needs. Professionals' approach to care seemed to alter depending on how 'connected' they felt with patients.

Nurses were the only permanent members who were continually with the patient throughout the patients' stay and were the 'fulcrum': being patients' advocates, delivering physical and 'narrative' care and talking socially and meaningfully with patients about their illness on an ongoing basis. On both wards it was nurses who tended to know the patients best, acting as their advocate and also being involved in delivering physical and psychosocial care.

There were also distinct clinical symptoms that related to the cancer type and cancer trajectory. For example, patients with lung cancer had a shorter journey than those with breast cancer. Patients with lung cancer were admitted as acute admissions to the medical ward, due to its respiratory specialty; however, the shorter trajectory of their illness and the increased presence of multimorbidity may have merited participants going to a place of care which was more suited to patients with a shorter lifespan, such as the specialist ward where they may have been known from before. This organization of emergency admissions led to fragmented care.

Inappropriate assessment within the specialties of oncology and gerontology gives salience to this current study, which explores the *processes* of care importance for interdisciplinary work. It is recognized that the focus of care should be underpinned by the needs of the older person with cancer. This lack of assessment found by this study was

further augmented by a specialty that is pluralistic in nature (medical ward) and does not truly reflect the needs of the older person with cancer. Patients also lived with uncertainty which was also due to a lack of assessment. In addition, a fast turnover may encourage perceptions of giving appropriate care for the disease and ignore the characteristics of being an older adult.

Assessing functional status would be valuable in allowing an assessment of how current treatment or symptoms are affecting existing morbidities and life goals. Considering Janet's arthritis in conjunction with her breathlessness could have provided a better assessment of how she would manage her activities at home. Assessing Ruth's lack of support at home might have indicated what further help was needed to protect her wellbeing, as she lived in an area where she might be in danger.

Pre-existing conditions, such as cardiac disease, will affect what type of chemotherapy a patient requires. David required a chemotherapy drug that has cardiotoxicity as one of its side effects (as already described). Impaired cognitive function may also affect patients' understanding of why they are taking medication. Bertie, for example, may have had cognitive impairment due to analgesia and/or deficits in his central nervous system. Addressing the significance of growing old would allow such patients to discuss how their illness has affected them regarding their life course[73] and life context.

Mary discussed how her life as a grandmother was important to her and how she liked to

[73] The life course is a culturally defined sequence of age categories that people are normally expected to pass through as they progress from birth to death. Included in the cultural conceptions of the life course is some idea of how long people are expected to live and ideas about what constitutes 'premature' or 'untimely' death (Phillips et al., 2010).

be known as a grandmother rather than just a ‘breast cancer patient’. Jinty was a nurse and found it frustrating that her former role was invisible to the nurses around her (she had also worked in the same ward). Ultimately, considering these complex physical and psychosocial domains will allow for more of a holistic assessment, which will result in the identification of unmet needs.

Older patients are unique in the way they perceive their illness. Patients’ stories were complex accounts, which were interwoven with the features of their illness and the symptoms and side effects of their treatment. Participants often told intricate stories of their illness, which combined their past illnesses, losses, current symptoms, and treatment side-effects. There was sometimes little differentiation between the symptoms of their disease, the side-effects of their disease and the side-effects of treatment. This was different from the professionals, who saw the clinical domains of side-effects from treatment and symptoms in a clinical way, as more of a cause and effect, than in a life context.

There appeared to be no particular communication ‘process’ which gave patients permission to discuss their needs. Through a continual interactive process of meeting physical and psychosocial needs, patients and professionals generated a shared meaning which was social, but this was more by chance, due to the potential constraints of hospital organization. The ‘ward as a halfway house’ held different meanings for patients as they negotiated clinical and social demands with professionals.

A further finding considered the definitional and conceptual issues relating to palliative care for older persons. It seemed that, for non-specialist professionals, palliative care and

being an older person with cancer were both equated with dying, resulting in a compartmentalizing of end of life care. As transcripts were continuously reviewed and re-analysed, findings indicated that the transition to palliative care seemed to be secondary to the overall focus of care. It seemed that the acute culture towards patients in both wards often led to a lack of recognition for palliative care. This study confirms that significant barriers exist in the provision of palliative care for older patients with cancer in acute settings, due to a lack of time, intra-professional tensions and a deficiency of education in gerontology, cancer and palliative care. Focusing on interventionist care with a curative intent was identified as contributing to the delay on the specialist ward.

In the sum, the 'MindMeister' map on page 133 highlights the range of themes which characterize *person-centredness* within each ward. These attributes, as identified in this chapter, include the need for coordinated care, working with patients' beliefs and wishes to ensure the ward is a clinical and emotionally safe place. Part of being 'clinically' safe is how symptoms (treatment, disease and multimorbidity related) are managed. To be emotionally safe is understanding how patients negotiate individual wishes which form a legitimate basis for decision making. What helps this knowing is the trust and familiarity that is generated between patient and professional over time. Thus a person-centred culture is generated through the notion of sameness and familiarity over time. The contextual nature of the ward activity means that this sense of knowing is more prevalent in a specialist ward due to the very nature of caring for the patients throughout their journey.

As part of being familiar with caring, professionals need to be educated in knowing their own values towards the older person with cancer and being a facilitator and patient's

advocate in helping patients in their decision making.

Studies have reinforced the inequalities of access to care, a lack of coordination (Campbell et al., 2001; Jiwa et al., 2007; Stevenson et al., 2003), with less access to specialist nurses (Department of Health, 2012a, 2012b). This current study explored more closely the interpersonal dealings between older patients with cancer in two ward settings in a cancer unit focusing on attributes within the ward which facilitate therapeutic relationship. This study also considers the importance of place and space such as being with other patients and the experience of supportive care.

As cited from previous research relating to ward settings (McCormack and McCance, 2010), an 'idio-culture' is when there are competing clinical influences from different aspects of care delivery. How an 'idio-culture' is experienced is dependent on the patterns within the ward culture (Plesk, 2001). Manley (2008) and McCormack and McCance (2010) argue that, within a workplace, patterns are associated with specific values, beliefs and assumptions, similar to Schein's levels of culture[74] (Schein, 2004). McCormack and McCance (2010) support that wards have different 'idio-cultures'. The importance of *how* care delivery is undertaken is salient for this study, locating the process within a ward context. However, organizational constraints intertwined with a lack of appropriate skills reinforced an 'idio-culture' that was fundamentally flawed in some ways to care for this group of patients. These organizational and professional attributes, such as poor staffing,

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[74] Schein's levels of culture are artefacts (what is seen or heard); language, stories, myths.

Espoused values; (what is lived); individuals have shared values in a care setting.

Basic assumptions (what does it mean); meanings of the culture that emerge through articulation of shared values through learning (Schein, 2004, pp. 111–112).

having less access to specialist nurses, have been stated in other studies (Mohan et al., 2005; Wood and Ward, 2000).

Therefore, considering the need for patients to feel familiar and to have a sense of significance, there is a clear need for a person-centred approach to care which generates familiarity. 'Person-centredness' (McCormack et al., 2002; McCormack, 2003; McCance, 2003) encompasses the context in which a patient is cared for and recognizes supportive organizational systems and the processes which promote personhood (McCormack et al., 2002; McCormack, 2003; McCance, 2003; Nolan et al., 2003). The promotion of person-centred care has been of importance for health services, particularly in reducing implicit ageism in the NHS (Nolan et al., 2003). Departments of health and charitable bodies have recognized that person-centredness has been a challenge, particularly for older people within acute ward settings in general hospitals, due to the lack of gerontology expertise and the context of care not being conducive in a therapeutic sense (Health Advisory Service, 1998; Help the Aged, 2000). Hickman et al. (2007) carried out a literature review which related to interventions that would improve care outcomes. Twenty-six studies (controlled trials) met the criteria. Interventions included emphasis on discharge planning, enhanced communication between care providers across the continuum. Recommendations were to have a specifically designed unit which emphasized discharge planning.

From a clinical perspective, there have been many studies that have reinforced the need to consider age-related and cancer-related domains (Beechey-Newman and Fentiman, 1998; Hurria and Lichtman, 2008). Realization of the difference between age-related physiological decline and other cancer and treatment-related symptoms is important, as the

former relates to functional decline with age while the latter relate to disease. These domains, augmented with an older individual's functional status, comorbidities (medical conditions, cognition), nutritional status, psychological state, and social support creates a complex picture which cannot be appreciated without a systematic assessment (Hurria et al., 2005). Given et al., (2001) followed a sample of 841 patients with breast, colon, lung and prostate cancer over the age of 65 and found that patients who reported pain and fatigue were those with multimorbidity and lung cancer at the late stage of disease. Both pain and fatigue are associated with a high number of other symptoms (Miaskowski et al., 2004; Bergman et al., 2007; Berkman et al., 1994). This finding is in accordance with other studies, which confirm pain as a common symptom for patients who also had other comorbidities (Reiner and Lacasse, 2006). Given and Given (2008) discuss the complexity and interplay of treatment, multimorbidity and symptoms.

Kelly (2012) in his editorial paper discusses the challenges of being hospitalized and living with the feeling of disappointment and with uncontrolled symptoms. He talks of the importance of acknowledging and understanding the meaning of life as a precious gift. Kelly reinforces the importance of clarifying and negotiating a more mutual way of making meaningful outcomes from palliative care. Findings from this current study would reinforce these recommendations.

This current study demonstrated that in relation to cancer and in consideration of the life history of older people, was dynamic in nature, involving an iterative process of looking back and looking forward. Helping patients to make sense of their illness in relation to the greater context of lives and experiences of older people is essential to address social and clinical expectations.

This study has highlighted the importance of social interaction and of providing a clinical space for older people with cancer which is clinically and physically safe. A study reinforced that there are unrecognized tensions in family members delivering care (Exley and Allen, 2007). The study emphasized the importance of care-giving in a hospitalized setting where there is less strain for family members. The 'therapeutic milieu' which is created on the wards through familiarity and trust reinforces the importance of being with patients in a clinical and social sense. The finding that older patients liked the sense of familiarity is also supported by the work of Duggleby et al. (2010), who explored the experience of older people in rural settings with advanced cancer. Their findings indicated that being in a small community facilitated supportive care. This current study explores further how professionals' interactions encourage particular discourse from patients. This is significant in that human beings are social and need interaction to stay alive (Kravdal, 2001; Wells and Kelly, 2008). This is supported by studies within the care environment that argue that professionals should 'be with' and demonstrate engagement with patients (McCormack and McCance, 2006; McCormack, 2004).

Seeing palliative care and dying as the same, rather than distinct concepts, has been supported by other studies. O'Neil et al. (2008) suggest that this perception of palliative care equalling death further complicates the implementation of 'continuous palliation', which is advocated in geriatric medicine (O'Neil et al., 2008). Gardiner et al. (2011) recommend the early introduction of palliative care for older people, to ensure improvement in end of life experiences. This could be further endorsed considering the multimorbidity of patients and multiple symptoms.

To further complicate the problem of ensuring continuous palliation, research studies already discussed in the literature review demonstrate that professionals are expected to provide cancer care for older people in both non-specialist and specialist settings (Puts et al., 2010; Mohan et al., 2005; Chouliara et al., 2004b). However, there are conflicts with inadequate assessment and treatment, showing a lack of consideration for gerontology *and* cancer care which is common for this group of patients (Puts et al., 2010). There were also unclear referral guidelines for geriatric medicine. As identified in the literature review, the two studies by Froggatt (2004) and Hockley et al. (2005) gave further support for this current study in recognizing that patient care is affected by professional specialty, access to oncologists and familiarity both with individual patients and their specific diseases, especially considering the aspects of old age *and* the need for continuous palliation. The importance of expertise in gerontology, as well as increased access to geriatric services, was implied but not made explicit in Froggatt's study (2004).

The finding that there are challenges in applying palliative care has been supported by the work of others. Roche-Fahy and Dowling (2009) interviewed 12 nurses, exploring the experiences of nurses who provide comfort to palliative care patients in an acute setting. Their findings revealed the challenges that non-specialist nurses have in the philosophy of palliative care. This current study builds on that knowledge, considering various perspectives from different professionals, and gaining insight into the multiple realities and meanings people attach to cancer care for the older person. Little is known about the barriers to providing cancer care, palliative care or both within a medical and specialist ward in a general hospital. The comparative perspective of this current study is unique, as it looks to the societal, professional and individual perspectives of how the older person

with cancer is perceived. The literature review has considered palliative care delivery in a care home setting (Hockley et al., 2005) and other studies have looked at the challenges in delivering care in a medical ward setting (Roche-Fahy and Dowling, 2009; Gibson and Grealish, 2001). Studies have shown that joint decision-making between cancer care and geriatric medicine is preferred, as it ensures a more rigorous assessment of patients' needs (Puts et al., 2010; Harrison et al., 2009).

From a conceptual perspective, findings from this chapter have inferred the clinical tensions of having cancer and being old. Self-stereotyping from patients may reinforce false images of the patient, as professionals withhold information and older people put their trust into health care professionals believing they know 'things we don't'. Thus, social constructions intertwine with clinical practices to reinforce the powerlessness and vulnerability of the older patient with cancer.

This chapter has considered the design of the ward, different professionals and patients with different diseases and how they progress through the different transitions of the process of hospitalization. It has illustrated the prevailing social construct of the older person, which is intertwined with cancer and palliative care. Adding the image of cancer to being old appeared to be an unfavourable connotation for professionals *and* patients. Professionals conveyed this as 'old people tend to not make a fuss' yet also perceived them as being over-dependent at times. The intertwining of being old and having cancer was perceived as disintegration, and cancer and death as a continuation of this.

This current study reinforces the notion that there are gaps in education and continuous learning for both cancer *and* gerontology. Specific gaps relate to a lack of understanding

of cancer and palliative care and how this relates to knowledge of disease and symptom control. Better management of patient transitions to palliative care would incorporate the management of the patient's supportive needs while addressing one's own societal and individual identities.

The next chapter will look in more depth at the coping strategies of older people and the interactive stance between patients and professionals, and will explore how a therapeutic relationship is built in relation to emotion management. The societal and individual social construct of the older person is discussed further as emotion management is explored.

CHAPTER FIVE

Emotion Management

Introduction

The previous 'care environment' chapter provided an overview of the *focus of care* in two ward settings comparing patients' and professionals' perspectives within the context of care. Prerequisites to enabling care delivery such as type of ward and patient type were described. Findings identified that *the two care settings* were not always appropriate for older people with cancer, given their stage of cancer and the need for continuity of care throughout the trajectory. The *focus of care* led to admissions being acute but transient in nature, thus lacking holistic interventions at times (this was more prevalent in the medical than in the specialist ward). The two ward settings were to a lesser or greater degree *'a halfway house'* when considering physical and emotional transitions. In addition, physical transitions were seen as complex, as older people had functional issues from the ageing process *in amongst* their existing disease.

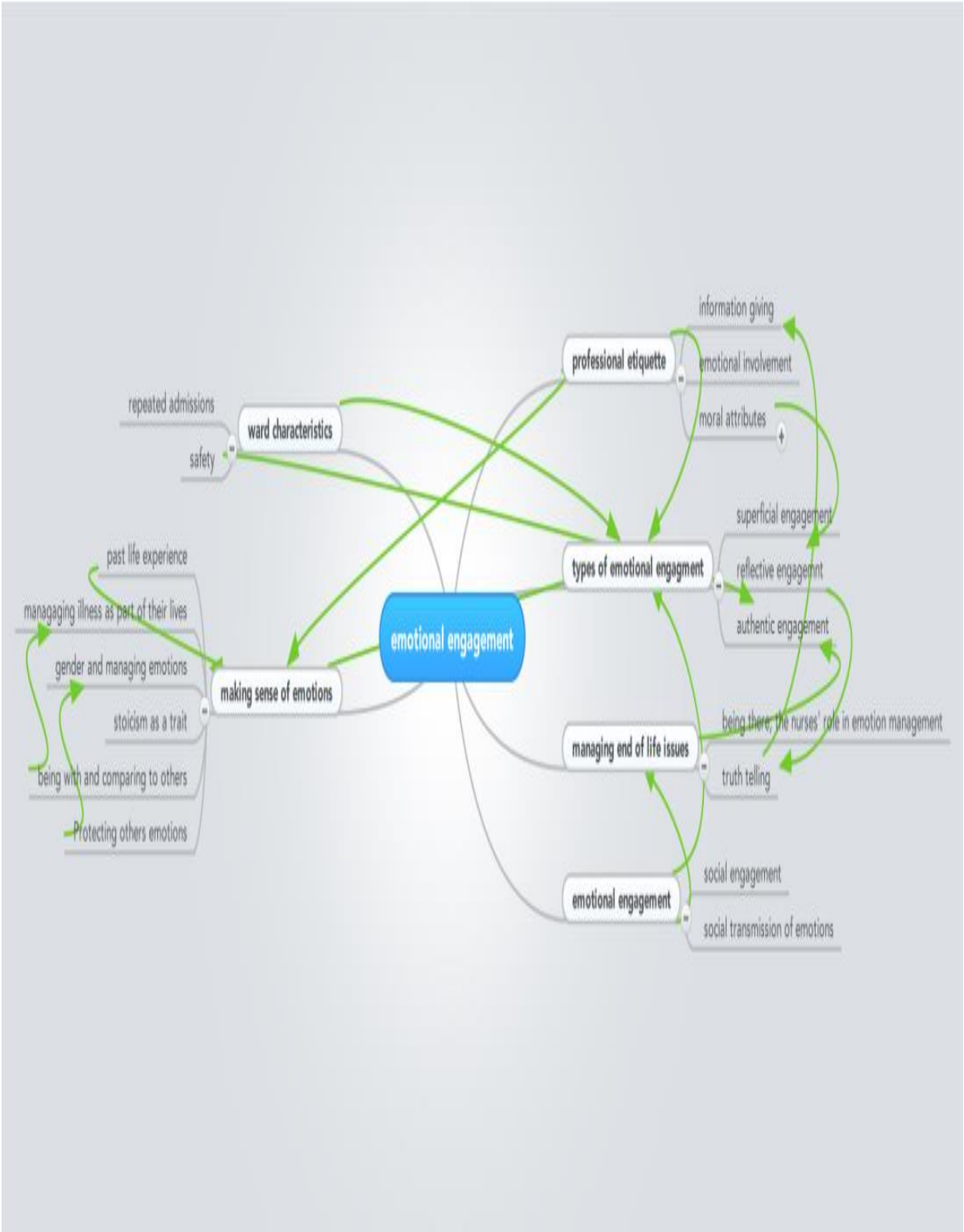
This chapter will further explore the experience of hospitalization in relation to *emotional engagement* between professionals and the older person and how patients managed their emotions to protect others. It will discuss *six* major themes. The *first* theme, *ward characteristics*, relates to the context of how patients are managed. The *second* theme describes how *patients make sense of their emotions* considering their past lives within the greater context of their personhood; gender and being stoical. The *third* theme illustrates

how professionals engage with patients using a *'professional etiquette'* to protect themselves from being too emotionally close while saying or doing the right thing. The *fourth* theme, *'types of emotional engagement'*, identifies that professionals used three forms of engagement with patients. These forms are 'superficial', 'reflective' and 'authentic' engagement. The *fifth* theme, *managing end of life wishes*, establishes the challenges for professionals in the transition to palliative care, particularly decision making (cessation of treatment) and truth telling. Findings gave insight into the *way* nurses manage the older person with cancer. When professionals were 'authentic'[75] they were reflective, which promoted mutuality between the older person with cancer and professionals. It was significant that nurses were able to 'be there' in an emotional sense through social interaction focusing on the person. The final, *sixth* theme, *emotional engagement*, considers the importance of social chatting to reinforce engagement with patients. Importantly, education in cancer *and* gerontology care is essential to crystalize professional values, improve skills in emotional engagement to ensure an authentic relationship.

Table 12 illustrates the themes from the data and how they relate to one another:

[75] The 'authenticity' relates to drawing on a sense of self, which allows individuality, as it is linked to emotion, memories and the sharing of this knowledge through relationships (Theodosius, 2008).

Table 12: 'MindMeister' map: emotional engagement



Ward characteristics

As discussed in the previous chapter, the medical ward had many *organizational factors (staff shortages, an increase in demands*) which hindered giving patients time to discuss their emotions. The specialist care environment gave more of an opportunity for enabling the sharing of emotions. The factors of gaining information, having *familiarity and trust* for professionals (especially with repeated admissions) generated a *therapeutic relationship* and enabled the older person with cancer to manage their illness. While on the medical ward this was less opportunistic. Patients on the medical ward also had less time to adjust to their illness due to the 'shorter cancer journey' having been diagnosed at a later stage than some patients in the specialist ward.

The specialist ward enabled patients to talk more about their experiences. While on the medical ward there was less time, with a busier pace, to discuss the emotional aspects of what it means to have cancer when older. Two ward settings, while being perceived 'as safe' in some ways, but were *not always* safe in a physical (symptomatic relief) *and* emotional sense. Professionals on the specialist ward had more time to reflect on care. This increased familiarity and trust may have facilitated a person-centred approach to care. While on the medical ward there was less of an opportunity to engage with patients.

In sum, the differences between the wards were in relation to having a sympathetic presence. Having time, the appropriate education, and building up a therapeutic relationship were all attributes to generating a *person-centred approach* to care.

Making sense of emotions

In the following section I will discuss findings related to emotion management. Patient and professional accounts will be contrasted in a general and specialist ward. The first section relates to the role of past life experiences.

Past life experience

Accounts intertwined with the past and the present, which gave a clear message that patients did not consider their diagnosis as a one-off event but saw it in the context of past losses and previous cancers.

On the medical ward, Janet talked about how the death of her husband left her alone, bringing up the children (she cried), while also speaking of the immense difficulties she had in getting out of her house into the garden (she was a keen gardener). Ruth discussed incapacitating symptoms, such as continual breathlessness, which restricted her ability to go to bingo, visit her grandchildren or collect her newspaper. Patients' past lives and losses were intertwined with their present 'total' pain.

For some participants, the context of past life experience served to generate representations of their cancer. Patients' past biographies served as a pool of memories, which often related to past deaths of their spouses (four participants' partners had all died of cancer). On the specialist ward, Colin, who was 78 years old, described how his wife had died on the same ward (specialist ward) where he is now being cared for. Biography in this case not only reflected past experience of illness but experience of loss through the death of his wife. From a ward perspective, familiarity reinforced 'sense of knowing' professionals from previous admissions. In Colin's example, this clinical familiarity may

have fostered his acceptance of his diagnosis. It is unknown whether the professionals knew of his past experiences.

> You've seen and been through the whole lot of the thing; you know what's coming ahead, so you just have to accept it and that's it. (Colin, prostate cancer, specialist ward)

Colin then went on to discuss his *past illnesses,* starting with his 'broken hips', heart disease and prostate cancer, as a biographical continuation of having had many illnesses:

> In between that I got two broken hips. I was in here with two broken hips. A replacement hip, so, I had a lot going wrong with me because I had my heart and prostate cancer, too. I am not long finished with prostate cancer. (Colin, prostate cancer, specialist ward)

Another example was David, who cared for his first wife who died of breast cancer. His second partner had non-Hodgkin's lymphoma, and he had a past history of cardiac disease.

> My wife, she had breast cancer … my girlfriend, now she had Hodgkin's lymphoma … this is terrible for me, as I see that I now have it…. (David, leukaemia, specialist ward)

It was significant that both his former wife and girlfriend had different cancers, but that he saw each cancer as the same. He similarly saw his cardiac disease as another significant illness, reinforcing the intertwinement of past events making up how patients perceive the present. In addition, acceptance[76] of illness related to most patients who had reached the

[76] 'Acceptance' is defined as: The act of receiving what is offered, with approbation, satisfaction, or acquiescence (Wiles et al., 2008).

end stages of their illness. Patients understood that they were in the palliative care stages but felt that the social construct of being older was also a reason to accept their illness.

From a professional stance, perceiving older people as stoical may lead to the thought that older patients place less importance on their illness, but in reality it is because they are looking at their past as a way to make sense of their present illness, thus being accepting rather than curious.

Professionals who visited both wards recognized patients' lives are as important as to how they manage their illness. Clinical Nurse Specialist Firth stated how older people 'bracket off' their cancer, preferring to talk instead about other essential aspects of their life which they perceive as important:

> Older people don't tend to make a fuss. They are happy going along, some of them are so easy to look after and it is great. You can sit and have a chat with them. When you sit and speak to the older person as well, their conversation isn't centred round their disease…. They'll speak about bits and pieces of it but then they will go into how they potter about in the garden and how their tatties have grown this year. (Clinical Nurse Specialist Firth, lung cancer)

It is interesting how most of the professionals, as in the example above, discussed in general how 'easy' older people are to manage. The perceived acquiescence of older people appeared to give mixed messages to professionals. Professionals appeared to see them as uncomplaining at times and therefore not in need of psychosocial support. Professionals also drew upon societal perspectives while the patients reflected on their past lives as a resource, thus shows a focus in different aspects of 'discourse'. In addition, previous findings also highlighted how professionals can often focus on the clinical specialty of the patient rather than the person.

Professional accounts in the specialist ward highlighted a place of care and 'notion of sameness' (see page 153) in that patients all had cancer. It could be that because of the focus of care being more cancer related, professionals tended to normalize the perceived impact of cancer for older people. However, professionals on the specialist ward had time to listen to patients' past lives, perceiving them also 'as part of the family'. Therefore a *clinical and personal* notion of familiarity engendered a person-centred approach.

I reflected on my field notes at the time:

> I find it difficult to see how people are seen as the cancer patient and/or the elderly person. Patients' stories make them individual, so I see stereotyping as unhelpful and perhaps used to surmise when professionals do not know patients and have not had the opportunity to listen to them (field note 13).

While person-centred factors such as familiarity and 'notion of sameness' helped patients *and* professionals to manage their illness, physical constraints on life such as existing treatment and symptoms impacted on how patients lived their lives. The similarities and contrasts between patients and compared to the two wards will be discussed in the next section.

Managing illness as part of their lives

Patients undergoing chemotherapy and/or radiotherapy also had symptoms from their illness and multimorbidity. As a result they experienced constraints on their social life. An example was David, whose side effects of treatment affected his ability to go on holiday. Andrew could not enjoy his golf. Alexander could no longer play bowls, as he could no longer walk. However, most of the accounts from patients, particularly those on the specialist ward, demonstrated an ability to manage the effects of treatment and 'get on

with it', showing that they still tried to enjoy their life. Patients on the specialist ward appeared to cope more with life outside the hospital, which may have been due to the care setting and/or severity of symptoms:

> I find controlling food more difficult. Controlling food is only to make sure that I don't take anything that's got bacteria. That's why I will not take a rare steak, soft-boiled egg or anything like that; just sensible really. (David, leukaemia, specialist ward)

Most of the patients in this current study had *progressive disease*, but some still maintained their lifestyle as much as they could, despite having insight into their progressive physical decline. Whether symptoms were acute or chronic, patients tended to look to their future, and reasserted their life goals accordingly based on their functional status and perceived quality of life:

> I will still attend Probus Club[77] when I can – it allows me to be seen as I was when I was teaching (Mary, breast cancer with metastases, specialist ward).

> I will sit and watch at the bowling green. I can't play now due to the pain and my legs … my son will take me to watch in the car with my wee dog…. (Alexander, prostate cancer, medical ward)

David had cardiac disease and hairy cell leukaemia. Despite two chronic illnesses, David explained that he could still go to church and do all the things he liked when he was not having chemotherapy. Both David and Mary (both specialist ward) tended to minimize the

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[77] The Probus Club is an internationally renowned group, which was previously known as the Rotary Club. Known for their informality, the Probus Club meetings may consist of a rendezvous for morning coffee, followed by a talk by an invited speaker on a topic of interest to the members. Members themselves contribute to the programme with accounts of their experiences or by providing entertainment at festive occasions.

impacts of their illness by maintaining as normal life as possible. Although Mary was in the palliative care stages, she tended to normalize her illness with just 'getting on with life':

> Whenever he says, 'Come back next month' they have got to catch me and then you come back and they will say, 'Come back next month' and we are off again. I am not going to stay put…. (Mary, breast cancer with metastases, specialist ward)

In comparison, Janet looked to her death, in the expectation of seeing her husband after she died:

> You have to fight when you can but also just accept … I want to be with Johnny and perhaps then it will make it all better. (Janet, lung metastases, medical ward)

Findings indicated that how they managed their illness had an effect on their emotional management of the illness (Janet and Mary were both in the palliative care stages). Mary was as symptomatic as Janet but was more *informed of her care*. Mary had also lived with her disease *longer* than Janet. Mary was cared for in the specialist ward and merited professionals' roles as supportive, knowing her needs well, while Janet was an emergency admission to the medical ward and did *not know* the professionals. It could be argued that familiarity with professionals may have given Mary more positivity for life that is there, while Janet was looking to her death and how she wanted to die. The differences in the ward appeared to be that *all* patients tried to manage their illness and their social life but patients on the medical ward had less functional capacity.

However, professionals appeared to look to the treatment (specialist) or the symptoms (medical) rather than the aspects of how patients' illnesses affect their daily living. This

could also be linked to the *focus of care*, as professionals in the medical ward were mindful of their next place of care while the professionals on the specialist ward were planning their next admission for supportive care (treatment).

While this section has considered coping mechanisms, it is equally important to consider the influence of a patient's past lives, which further advances the notion that as people become older a cancer diagnosis is managed differently by the life experience of the person. Gender was another dimension that challenged participants in wanting to not be just seen as a patient.

Gender and managing emotions

This section will discuss how patients manage their role as a woman or man while experiencing their illness. Professional perspectives will also be discussed. Accounts from *patients* demonstrated that cancer was expressed in terms of their gender in how they managed emotions and protected others. As a result, patients on both wards discussed their diagnosis in relation to the social roles of grandmother, husband, and/or wife. One of the ways patients normalize their illness is through focusing on their gender-related identities.

Mary discusses the multiple perspectives to personhood, acknowledging herself as a grandmother and a woman when speaking with a nurse:

> It was woman-to-woman not granny-to-granny really … she could see me as a woman … woman-to-woman and here was something that she wanted to share with me and that made me feel like a person…. It just made me feel that, yes, she could see me as a person. (Mary, breast cancer with metastases, specialist ward)

This current study also highlights the notion of invoking *social talk* as an important aspect to managing illness by re-establishing the social identity of being a person rather than being labelled as just a cancer patient. As patients were in 'same-sex' bays, this may have further reinforced their personhood and identity outside of being a cancer patient.

Some patients bracketed off their illness by looking at other aspects of their life, such as being a grandmother and babysitting:

> I look forward to seeing my grandchildren every Friday as my daughter goes out. I don't want them to know I have cancer. (Janet, lung cancer, medical ward)

Ruth focused on the importance of her role as a grandmother and a widow rather than as a cancer patient. She appeared to focus on her other identity rather than thinking of her illness, reinforcing the multiple identities the participants had within their family.

Participants talked of the sadness of not being able to care for their grandchildren due to their illness or not being able to visit due to fear of an infection (David and Mary):

> I cannot see my grandson. This arsenic is not good for my marrow … I cannot go to him in case I get more infection and then I can't get my tablets. (David, leukaemia, specialist ward)

Although some of the *male patients* also had children, they did not discuss their emotional bonds with sons, daughters or grandchildren, and were less willing to talk about these attachments than women. Most of the men mentioned their role within the family, but related this more to their past occupational role or their partner's reactions to their illness.

This current study advances the idea that females *and* males adhere to social norms and fulfil the emotional expectations of being a man or a woman whilst also being a cancer

patient. As participants appealed to other identities of themselves they perhaps ensured the impact of their illness was lessened as they acknowledged the many domains of their personhood and social expectations within the family, looking after others, such as their husband, wife and daughters (Mary, Janet). In the sample of ten patients there were four women who had grandchildren and siblings. They all discussed their role as a grandmother or mother as a fundamental part of their identity and part of living. It appeared that the women in the specialist ward looked more to the maintenance of their role, while women in the medical ward looked to their loss of their social and emotional role of being a grandmother. This not only related to their loss of functional status but to their impending death. From a professional perspective, gender aspects of the patients' social role were apparent, influencing the perception that men and women act in different ways in relation to their generation. This is exemplified in the quotations below:

> Elderly men seem to be more stoical than elderly women. They're still determined usually to do as much as they can, whereas elderly women do a lot more lying in bed to accept … that an age thing or a cultural thing? (Staff Nurse Gamlin, specialist ward)

> I think men are more stoic; they don't like to break down and show emotions. And yet you get the women as well that have got to be so; they're carers so they've got to be strong for their family. (Clinical Nurse Fenton, lung CNS)

Gender was related not only to how patients perceived their illness, but also influenced how they saw their social role within the home. Some professionals on both wards felt it was 'a gender generation' aspect to patient roles and how they assume certain expectations within relationships. Findings suggest that some patients were content to relinquish some roles during hospitalization. One female patient was very happy not to be making the tea

for her husband (as she was now labelled a patient) while one man stated he was doing more for himself in hospital than at home.

> To be honest I do more here for myself than I do at home … my partner, Carnella, loves to do everything for me, but here I just get on with it myself (Don't tell her I said that, he laughs). (David, leukaemia, specialist ward)

> The thing is, I always do the Sunday roast and worry about my man – what will he do … he is struggling a bit without me and I wish it wasn't like this at times but then I think … what can I do? (Mary, breast cancer, specialist ward)

A staff nurse reinforces this image of women 'doing everything' for their husbands:

> A lot of elderly men, especially the ones in their seventies or eighties, were men who used to get up and their wives did everything for them. They used to get up and go out to work, and the majority of wives didn't work and they would come home and their tea would be on the table, their clothes would be washed and they didn't lift a finger to do anything. (Staff Nurse Jeana, medical ward)

The above quotation was reinforced by patients' accounts as they discussed some domestic duties from their bedside. One staff nurse remembered how some women still continued to look after their husbands even though they were in hospital:

> [The wives] were shouting the orders when their husbands are leaving, 'Remember that's in the fridge, darling.'(Staff Nurse Gamlin, specialist ward)

Gender-related identities oscillated between physical and emotional expectations. Physical expectations related to doing more or less for themselves physically. Emotional expectations related to protecting others. Hospitalization appeared to exercise the female participants as they tried to maintain their role while still being hospitalized (in the specialist ward), while men in hospital still accepted that they would be cared for by their

wives (in both wards). Gender was embodied as part of their identity and personhood. Professionals perceived the attributes of gender as a constituent of generation as men were not as proactive as women. All professionals did not seem to consider the gender aspect of the patient as important in their holistic assessment of care. While patients' gender was an essential social force in the experience of ageing, the greater discourse of being older influenced how patients were expected to behave. This related to being stoical, which will be discussed in the next section.

Stoicism as a trait

Some professionals perceived older people as stoical about their illness. Similarly, it appears that, as a result of 'being stoic', some patients did not disclose their symptoms. Older patients seemed to accept their pain as part and parcel of having cancer:

> A lot of them get frightened, frightened they are going to die in agony, and a lot of it is trying to reassure them. You don't need to be sore and you don't need to be really short of breath and you don't need to feel like you are choking all the time and there are things we can do to help that, to make that easier for you. You don't have to die screaming in pain, that doesn't happen like it used to happen. (Staff Nurse Jenkins, medical ward)

Staff Nurse Jenkins had a post-registration course in palliative care and her expertise is reflected in the above quotation. Findings identified that participants thought that having cancer commonly resulted in death, so asking for further information seemed futile. Data from this current study did have a 'gender and generation' aspect, in that men were more accepting of their care while women in the study were more reflective and analytical about the care they received. There could also be a factor of men being stoical about wanting information:

> Men don't tend to seek help … gentlemen don't look for help and they need it as much as everybody else. And that was the challenge for me to try and address that. (CNS Fenton, lung cancer)

In the *medical ward*, patients were often going to another ward setting where another set of negotiations for identity would begin. However, in most participants this addressing of their identity may be their penultimate as they reached the end stages of life.

The section on 'experiencing symptoms' (see page 165) in the two wards suggests that there could have been more of a holistic approach to the older person with cancer. Findings from this study give a clear message that professionals' perceptions of illness could be better understood if there was more appreciation of the greater context of being older and in recognizing the many social identities and emotional strategies which the older person with cancer may undertake.

This section considered that the way women and men managed their illness was related to gendered expectations. Professionals also drew upon different identities, focusing on the older person as 'being a patient'. Tensions seem to arise in professionals' ability to look at the person, while also being influenced by social norms of how older people are perceived. From a patient perspective, these social identities were more visible when patients engaged socially with fellow patients in the ward settings. Interacting with others, reflecting on past memories and present interactions gave patients an opportunity to better understand their illness.

Being with and comparing to others

'Being with others' was a way patients managed their illness through interacting with others while living with their symptoms. The interaction helped them to manage their symptoms both physically and in an emotional sense. Without exception, patients were dealing with symptoms and some short-term effects of treatment. Participants in the sample who were with fellow patients tended to draw upon interaction with others to provide support and distraction from their symptoms.

> I have pain in my side and pins and needles from my treatment, but when I am with a fellow pal or patient this disappears just for a while…. (Alexander, prostate cancer, medical ward)

This process of making comparisons with others served the specific purpose of creating a sense of identity and mutuality with one another. Janet and Staff Nurse Krise recount in the quotations below the benefit of mutuality with fellow patients. Transcripts from the medical ward strongly indicated the benefit of being with fellow patients within the four-bedded bay, highlighting the importance of mutual support:

> When I was in here the last time, I made friends in the ward, and the lady in the next bed to me, she's covered with scars, she never moved and she was always smiling, and at night if she needed the toilet, I used to unplug her machine and put her into the toilet and told her to shout on me when you need back out. (Janet, lung disease, medical ward)

> It is nice to be in an area, a ward setting where you don't have to explain yourself to other patients because everybody is 'in the same boat'. In that instance, it wasn't actually to do with the staff, it was about other patients that made it nice for her [Janet]. And that feeling of having … there still is a stigma attached to having cancer. (Staff Nurse Krise, specialist ward)

These quotations highlight the value of being with fellow patients with the same diagnosis, which might result in making new friends. Janet, for example, recounted how she continued to contact the lady she met in hospital until her friend died.

Bertie had no family, so he found interaction with both patients and professionals very worthwhile:

> Well, I just chat with them as if they were my own. They are all my pals … (Bertie, prostate cancer, medical ward).

Other patients also felt that being with fellow patients served the psychological purpose of putting their lives in a better perspective by comparing themselves with others:

> There was this lovely girl that used to come in the same time as me … she was a young girl and very poorly … made me think at least I have had a bit more years to my life…. (David, leukaemia, specialist ward)

Reflecting on the spread of 'Emotional adaptations of the older person in two ward settings' in Appendix K, it appears that the process of comparison is opportunistic for some patients in this study in various ways. Firstly, it can be suggested that patients were able to interact with other patients, which afforded a further opportunity to seek meaning, identify and sustain a more positive outlook. Secondly, the experience of interacting with others within a hospital context was used as a vehicle for making sense of their expectations. Being 'in the same boat' also generated comfort from being with others in the same situation.

Another strategy used by other patients in the study was to make favourable comparisons between themselves and fellow patients. Sometimes this involved invoking age differences:

> R1: Especially in haematology, when they see young people, they will go, 'Well at least I've had a life, not like poor…' so they do almost take themselves out of the equation.
>
> R2: And more so in the unit, because they are all sitting together.
>
> R1: When they see young people they become quite, 'Oh, maybe I'm bad, but I've had my life, not like....'
>
> R2: And the fact in the unit they seem to take on almost a paternal role with the younger ones. You find the older ones will be comforting some of the younger ones, offering them their experiences, just naturally. (Staff Nurse Bell, specialist ward, focus group 1)

Thus, findings from the *'Being with and comparing to others'* theme served two purposes. Firstly, it acknowledged a process that patients used which was necessary to sustain their hope, perceiving people worse off than themselves. Secondly, comparing themselves to younger people provided justification for adjusting their emotional approach allowing them to acknowledge the trajectory of cancer and accept their eventual death.

Making sense of death was attributed to their past experiences of seeing their family members die. This patient with end stage lung cancer seemed to be resigned to her impending death and conveyed a sense of despair by making sense of her other family members' experiences:

> I nursed my mum and nursed my dad. My dad died the day he was to go into hospital. My dad used to scream for his jag, scream for it and I thought, 'Oh God, I hope I am never like that.' (Janet, lung disease, medical ward)

The following quotation is from Jinty, who had breast disease, and refers to the end of her life through comparison to her family. She had also worked as a nurse on the same ward in which she was now a patient. It is interesting that, despite her previous nursing experience, she relied on her past experiences with family and friends to make sense of her illness:

> A few of my relations have died with cancer. I had a cousin who died with cancer, and, more recently, my cousin's man, he died; they are all dying off. People don't live forever. But it is what they are having; it's [cancer] not a very nice thing to have. I would rather maybe just get run over or just drop down dead with a heart attack or something like that, but going through all this, is really tremendous, it is, it's really bad. (Jinty, Breast disease, metastasis, specialist ward)

Janet also attempts to locate her own experience through reference to past losses:

> I wish I could die like my husband … it is not nice to go like this … I would rather the heart goes than this. (Janet, lung cancer, medical ward)

It is of interest that both patients talked of wanting not to die from cancer and having a protracted death but hoping for a quicker death which was perceived as having a 'heart attack'.

In this study, the context in which participants discussed their illness influenced their perceptions in two ways: firstly, being older and acknowledging their past lives, and secondly, how they manage their emotions in relation to the current context of the ward. The code of 'comparison to others' demonstrates two things: firstly, the process of comparing themselves to others acknowledges an engagement with and ability to make

sense of their knowledge; secondly, comparison to others allowed patients to make their wants more positive through seeing others as ‘worse off than themselves’.

Findings demonstrate that patients tended to look back at their past loved ones and how they died in the hope that they would die like, or not like, them. Despite patients being hospitalized, they still related to their past experiences to manage their illness.

In summary, the structural aspects of the ward are important and provide different experiences (as identified in the section ‘Ward design’). From a social perspective, patients seemed to prefer the social interaction of being with others on four-bedded bays when comparing themselves to others.

The next section will discuss how patients managed other people’s emotions, which is key to understanding how patients disclose to others. While the social interaction of being with others served as a way of managing their illness, it is also important to consider how patients protected the emotions of their family and friends.

Protecting others’ emotions

Findings identified that patients protected their families’ feelings through a management of their own emotions, only showing positive feelings and hiding their inner fears. Both male and female participants perceived that they were the ‘glue’ in their families, holding members together. Janet, Mary, George, Andrew, Graham and Ruth all talked of their families in relation to protecting their spouses or siblings. Part of that protection regarded managing their own death so that it would be easier for their family:

> They [his family] will look after her [his wife], no doubt about it … you won't need to go to the undertaker and break her heart or anything because everything has been done. (Archie, palliative care, specialist ward)

Archie was managing the *practical arrangements* for his own death so he could protect his family and deal with their emotions. Whilst trying to cope with the physical symptoms of his disease, he still found the resources to prepare for his own funeral in order to help his family. Preparing for the end stage of life was significant for most of the patients in this study. Another female patient wanted to protect her grandchildren from the impact of her illness and impending death:

> I hope that it is the heart that goes first; it is a shock. I don't want my grandchildren to see me slowing, going in a bed and looking like this. I told my daughter not to tell them I had cancer. (Janet, lung cancer patient, general ward)

The above quotation demonstrates the fear which is perceived with a diagnosis of cancer. The patient also discusses how she is trying to protect her family. Another patient, Colin, discussed how he had told the family he was getting better, while deciding to stop his treatment due to the side effects of chemotherapy. He had previously had leukaemia and now had prostate cancer. I asked:

> Q: Have they said what treatments they can give you to help you?

> R: Aye, they were going to give me chemotherapy and I said to them I've had chemotherapy and it didn't agree with me; I had bother with it, so I just told her I don't want any more chemotherapy.

> Q: Is it just not agreeing with you, the chemotherapy?

> R: No, I was sick and I said I wasn't going to suffer all of this. If I was a younger person, I suppose you cling to life as long as you could, but me, I'm not worried now, not in the least. (Colin, prostate cancer, medical ward)

Colin went on to say that he believed in living the life he had with little worries at his age (77); all his family were doing well, and that was what mattered. His wife had already died. He had also had leukaemia. These past experiences may have been a resource for managing his illness and recognizing his end of life. He also stated that he was not going to tell his family that he was stopping treatment.

Another patient, Graham, also highlighted his acceptance of his situation. Graham's gesture of giving away his golf cart to his friend, knowing he could no longer play, symbolized both an acknowledgement of their friendship and his entering the end of life stage of his illness:

> I've known him for years – I just said take it, I will no longer be needing it … he will look after it for me … (Graham, unknown primary with liver metastases, medical ward)

Findings convey the complexity of emotions that occurs between patients and their families at the last stages in people's lives. This intricacy of emotions draws upon the strength needed in coping with a cancer diagnosis and dealing with death.

Emotional engagement took place both between patients, their relatives and between patients and professionals. Emotional management of patients occurred through pulling on their identities as a wife, husband and friend, not just as a cancer patient. Both Andrew and Archie were making *practical arrangements for their death*, giving away sporting equipment and having made funeral arrangements reinforcing a social and physical death.

Janet and Andrew also tried to hasten their death through hoping to die one way and through stopping treatment.

In this current study, findings indicated that patients often needed to express emotions and fears to gain emotional feedback from professionals. This was important as they could not express these emotions to their families (as they wanted to protect their family). Patients tended to respond to these 'cues' and express their own thoughts and feelings. Thus, some patients sought information from professionals as a way of showing their true fears, which they may not have had the opportunity to do at home if they wanted to protect their family. Professionals, however, tended to be more reluctant to express their own feelings to patients. This was evident on both wards. The section 'Being a patient' in the previous chapter explores this further.

'Professional etiquette'

On both wards there was a type of 'professional etiquette' involved in terms of how and when emotions could be shared. Findings highlighted that the code of etiquette acted as a 'filter' for managing difficult conversations. The in vivo code 'etiquette' describes the professional regulation of information, emotion and moral aspects when talking to patients. Analysis identified that there were three types of categories relating to the main code of 'etiquette'. These are:

- Information giving.
- Emotional involvement.
- Moral attributes.

Information giving

Professionals gave information relating to a patient's illness, as well as future plans, such as the next place of care. Patients were physically and emotionally dependent on professionals. They verified their dependency through trust (see section 'Trust' in the previous chapter). The section 'Being a patient' demonstrates that patients felt safe in relinquishing their roles and feeling protected while hospitalized.

Patients were thus dependent on nurses, in particular, to tell them the truth and give them information so that they could be involved in their care and make decisions about their life. Graham queried why health care professionals could not explain things in a way he understood. I asked him how he would like to improve his care. He replied:

> To get a fair deal, yes. I feel they could inform you more. Maybe there are certain things, etiquette, or whatever you call it, stops them from saying too much, because six to eight weeks ago I said to one of the doctors, 'What's your opinion, never mind your professional opinion, what's your opinion?' And he said, 'I'm not allowed to air opinions is the answer I could give you … what I think has nothing to do with [it].' The same when I asked about another doctor, I mentioned saying about this other doctor to him and he said, 'I cannot talk up for any other.' And they were to their own but not giving anything away to me. (Graham, unknown primary with metastases, specialist ward)

Graham explained that the doctor's lack of information made him feel vulnerable. Inherent in this quote is the power of medical knowledge fracturing the relationship between health care professionals and patients. Information was not always available due to specific times that this was shared (such as during ward rounds). Some participants had difficulty understanding what was being said. The way information was given was underpinned by how professionals emotionally engaged with patients and the moral duties inherent in their roles. Nurses played a valuable role in working more in a partnership with patients.

The nurses on both wards saw the need in taking time with patients and the importance of being with patients. As identified in the last chapter, a lack of time hindered the ability to give information (especially on the medical ward). It could also be argued that general nurses were not always equipped with education to give information to patients relating to treatment options. This was augmented by the high turnover of patients in the medical ward, and less information available as there was not a previous understanding of the patients' journey, and the complexity of their symptoms may have made decision making more complex (see page 159 regarding multimorbidity). In contrast, having a 100% cancer occupancy would have reinforced an understanding of ward routines which may have not been so evident in the specialist ward. While there were different levels of information giving on the wards, how professionals *engaged emotionally* will be discussed in the next section.

Emotional involvement

Patient communication involved conveying personal information, which in this current study related to a patient's diagnosis and the impact of their illness on their lives. All participants without exception spoke of the nurses in particular and how friendly they were. Common words used were 'having a laugh with them' and looking at them 'as friends'. This was more predominant on the specialist ward. This could be due to the fact that patients were with nurses more than other professionals. Patients also saw the nurses as more approachable than other professionals, as they saw the nurses frequently, whereas other professionals were only seen at specific times, such as when assessing their nutrition or helping them to mobilize. On the medical ward, talking to professionals was uncommon, as most patients were breathless and found talking difficult.

While patients asked questions about professionals' lives, there seemed to be an 'emotional etiquette' in operation, in terms of how professionals responded to this type of communication. Whilst sharing part of your life is seen as a valuable way to generate a therapeutic relationship with patients, some professionals felt there were tensions in doing this (this is discussed further below). Listening to patients' experiences is important in understanding how patients cope with their illness and reducing their feelings of vulnerability. Similarly, patients asking professionals about their personal lives may help them to understand and trust professionals.

Professionals appeared to balance being emotionally engaged with trying to say the right thing. Tensions in dealing with emotion resulted in some professionals being at risk of not knowing what to say to some patients, while other professionals focused on the societal discourses in understanding complex emotions from patients:

> Older patients are less upset about their diagnosis than the younger ones … they do not ask for much, which makes our job easier in a way…. (Staff Nurse Krise, specialist ward)

Most of the professionals' transcripts warned of the need to protect oneself at the expense of exploring more sensitive issues with patients. During the dissemination focus group, participants discussed the tension between the professional and the personal.

> Yes, it [etiquette] does act as a barrier at times when you need it. If you are vulnerable yourself and are looking for or feel affected by your patient's diagnosis and their reaction to it you can hide behind it, but always at some point it gets you. You deal with it eventually, I suppose. Etiquette, you need it, for consistency and professionalism. (Nurse Percival, medical ward, dissemination focus group)

Health care professionals discussed the tension of dealing with one's own emotions while caring for the patient. There were obvious implicit social rules relating to how patients interact. These were to not be totally engaged as a person, but more as a professional, and that professionals have to protect themselves because they are also vulnerable to emotional strain. It appeared that professionals on the specialist ward were more aware of their emotional involvement, having known patients over a period of time. In the medical ward professionals did not discuss the importance of not getting involved.

This was further evidenced in accounts between professionals in the semi-structured, initial and dissemination focus groups. Staff Nurse Jones discusses a doctor's reflection on the emotional work involved between patient and professional:

> I always remember meeting a junior doctor once and she said, 'That's terrible' you know, about this patient … 'Whoa, whoa, whoa, you have to stop right there, you can't think like that.' That is the challenge … there [are] some people that do get involved but I have never been like that, never, because I just don't, it's not that I don't think it is professional, I am not saying that, but I just think it is a coping mechanism is not to get too involved. (Staff Nurse Jones, specialist ward)

It was more difficult to manage communication than it initially appeared, as there is a tension between what patients expect from professionals and the resulting responses that professionals can give at times. Professionals warned of the need of protecting oneself while also being emotionally engaged:

> So, kind of distance ourselves from those and we kind of scatter round it and we do talk about other things, which all have their place, but we maybe miss out on some of the deeper things. So it's as we said earlier, getting that balance about sometimes being a wee bit more unselfish and saying, right this might actually hurt me a bit but it maybe wouldn't hurt to go there. I don't know if that makes sense (Chorus of 'It does'). (Staff Nurse Krise, specialist ward, focus group one)

While some professionals within the care environments give patients an opportunity to communicate and disclose true fears, professionals also reflect on their own feelings of hiding vulnerability. From the data, it seems that while there are rules which dictate not 'getting too close' to patients, there is also a moral duty to 'do good' by patients. Moral 'etiquette' governed how and whether patients were told information or not.

Moral attributes

Nurses commonly spoke of attributes of being 'moral'. Findings indicated that moral attributes to the nursing role related to the transition to palliative care (page 174) and challenges in decision making (page 176).

The fact that older people were perceived as not complaining, or misunderstanding (see section 'Misunderstanding') resulted in nurses wanting to take more time with older patients. In the medical ward, this was not easy, as there were many competing duties and priorities. In the specialist ward, this was more easily done, as explained by Staff Nurse Kew, who spoke of 'Being with patients rather than rushing out the door backwards.'

As previously discussed, patients were mostly in the palliative care stages and therefore they were going through periods of uncertainty about their lives. If professionals were unsure of clinical outcomes, they did not talk with patients about their diagnosis, thus protecting the patient from undue stress:

> If you don't know enough about a cancer diagnosis, then keep quiet … so you shouldn't be saying, 'You might get chemo or radium', and then the doctor comes back and says you are not getting anything, 'But the nurse said…' You should keep stum and say nothing. (Staff Nurse Jeana, medical ward)

> I think etiquette is a barrier and a hindrance both, because it is a barrier to the patient because they want your honest opinion and you can't go … sometimes you look at the notes. And you don't say it because you might be wrong.… But it is helpful, because sometimes you can make the patient worse by telling them what you really think. Because you think they are going to die in two months…. (Pharmacist Luca, specialist ward, dissemination focus group)

There was also the moral duty to care in relation to truth-telling (in a clinical sense). Previous findings identified in the last chapter related to paternalism, protecting older patients and withholding information. Another finding was that the tension in dealing with organizational and individual needs created problems for professionals in prioritizing patients' needs, particularly in the medical ward. The section 'Focus of care' also reflects this tension.

It appeared that the key to giving information and managing difficult questions was to be emotionally engaged with patients, listening to their life stories and assessing their behaviour and feelings. The importance of being morally aware of older person's needs was an important prerequisite to the skills and knowledge of a nurse. While being *morally* responsible was one aspect, being emotionally engaged with patients was equally important.

Types of emotional engagement

Professionals used many strategies to manage and share their emotions. These included the three categories of etiquette: informational, moral and emotional. A further three types of emotions appeared to be used when talking to patients were superficial emotions ('We are clowns'), reflective emotions ('That could be my mum in that bed') and authentic emotions ('I get too attached at times').

Findings identified levels of engagement reflecting the ‘connectedness’ with the older person. Each care situation that was discussed by professionals and patients involved an expression of ‘uniqueness’ based on the values and beliefs of both patients and professionals. However, as mentioned above, professionals engaged with patients’ emotions in three ways:

- Superficial engagement, which appeared to be acted out to comply with the remit of their role.
- Reflective engagement, where professionals emulated emotions by looking at the past such as the personal experience of cancer or with loved ones.
- Authentic engagement, where professionals conveyed expressions which were unconditionally given from the person rather than perceived totally within the remit of their role.

The superficial engagement was less engaging in intent, while the reflective emotional engagement was more of a process which enabled an authentic emotion. However, although this authenticity was unconditional in engagement, there was also an aspect of protecting oneself. This ‘emotional etiquette’ depends on not getting too close with patients. Thus, emotional etiquette acted as a filter. The three types of emotional engagement will now be discussed in turn.

Superficial engagement

Professionals had different care priorities; some focused on meeting physical needs and dealing with symptoms, while others prioritized getting to *know patients as a person*. The specialist ward tended to have the opportunity to do the latter due to the slower pace of the

ward and the increased familiarity over time from return patients, while the medical ward was more focused on getting patients to the next place of care. This is not to say professionals were less caring on one ward than another, but more that the *specialty and pace of care* influenced nurses' ability to be emotionally engaged. Nurses appeared to be emotional jugglers and were able to adjust their performance, choosing to 'match the feeling with the face'. One staff nurse stated in a focus group:

> We are like clowns and change our faces as to what patients want from us. (Staff Nurse Krise, specialist ward)

The quotation from Staff Nurse Krise expresses the notion of superficial emotions when engaging with patients. The patient who was a nurse on the same ward for 15 years in which she is now a patient comments:

> Her vibes … I don't know how to word this to be sociable. My vibes are the very same. I don't know how to take her, and I don't know how she takes to me but she's a very funny person. I want to be sociable with everybody, but she is a very funny [researcher's emphasis] lassie. You can see it in her. I don't know if she likes me and, to be honest with you, and she doesn't like me why does she not tell me, then maybe get it out of the blue. But she can be a funny person. I can be funny as well, but not like that. (Jinty, breast cancer with metastases, specialist ward)

This tension between clinical and social perspectives demonstrates that this professional is strange or confusing to the patient. Reflecting on the quotation, it appeared the patient was relating to the nurse's moral attributes. The patient has an idea that her expectations are being breached. During the interview, it was clear that the nurse on the ward was not meeting the emotional needs for the patient. The patient (who was a previous nurse on the same ward) could reflect on her professional past as well as her experience of being a

patient. The nurse was not emotionally engaged and perhaps could not allow her past feelings to be involved, especially when the patient was a fellow colleague. It could be suggested that, as a result of the nurse protecting herself, she jeopardized fully engaging with Jinty. This is also reflected in the code of ‘professional etiquette’, as nurses do not give information to patients if they are unsure and ‘keep stum’ in order to both abide by professional etiquette rules and protect the patient.

The section on the ‘Transition to palliative care’ (p. 174) highlighted how older patients were not told about the rationalizing of medicines. It could be argued that this lack of information causes further emotional disengagement. Professionals used words such as ‘easy to manage’, ‘less upset by diagnosis’ and ‘easier to care for’, which demonstrates a less individualized perception of what older patients really want, reinforced by the perceived societal values of the older person. These themes identified assumptions and perceptions (which existed on both wards) which converged to create health care stereotypes of the older person with cancer. However, to hinder these assumptions professionals appeared to use all three types of engagement to enable appropriate care for the older person with cancer. The link between the levels of emotional engagement is discussed further in the next section.

Reflective engagement

This study has demonstrated that reflection enables professionals to manage emotions. Professionals used etiquette (all three categories) to make choices in how they care. In this study, professionals on both wards enacted emotional engagement in two main ways. One way was to look at their own experiences in caring for someone with cancer or, in the case

of one professional, having cancer themselves (Staff Nurse Granger, specialist ward). The other way was to reflect on the present situation. When they recounted on their present situations with patients, they appeared to disengage and reflect before returning to the situation again. They reflected not only on emotional conversations with patients, but also looked back at their own pasts and considered how this informed their care delivery. This process of reflection seemed to be an 'emotional check' reminding them of their own values, which could reduce the societal aspects of ageism. Staff Nurse Krise acknowledged empathy for a patient who was more ill than first thought. Here she demonstrates a reflective response:

> I think it is harder if they get a diagnosis that you, because you are nursing them, and you don't think that their condition is that bad, because they are masking it to a certain degree, as older people tend to hide their pain … and if they get a diagnosis of cancer, then that's very hard because you think, 'My God, how can that be?' (Staff Nurse Krise, medical ward)

From the above quotation it could be argued that Staff Nurse Krise is reflecting on her own emotions and feelings for the patient. She also is recognizing the fact that older people may mask pain due to stoicism. This is also exemplified in the quotation from Staff Nurse Jenkins:

> If you've experienced, as you say, a loved one with cancer as well, that informs how you care for a patient. (Staff Nurse Jenkins, medical ward)

Professionals discussed their *own past experiences* of having a loved one with cancer, reflecting on emotions which were similar to patients in dealing with their losses. Some professionals felt having had these experiences improved their ability to deal with emotions with patients. Professionals also felt that being older themselves added to their

emotional competence within their roles as caregivers, due to having more life experience and having suffered losses themselves (one professional interviewed was a cancer survivor). It could be argued that due to a lack of education (especially in the medical ward) professionals tended to reflect more on their past lives than past experiences and education.

Reflection enabled professionals to think about the care intervention and thus to be more empathetic by, for example, looking back on how their loved ones were treated. In this study, when professionals reflected on care it allowed them to focus on their values and try to understand the patients' holistic needs. The importance of reflection allowed the evaluation of care, ensuring authenticity, which facilitated a meaningful engagement with patients. It could be argued that on the medical ward as a result of the pace of the ward professionals did not get the opportunity to reflect on their care. While on the specialist ward this was more prevalent as professionals had one specialty to relate to and thus perhaps generated a shared sense of a philosophy which may not have been so easy on the medical ward.

Authentic engagement

Findings demonstrated that to be authentic it is important to consider the meaning of individual relationships and how this relates to human engagement. Part of that engagement appeared to be present when professionals had a deeper insight into the person's needs. One way professionals gained a deeper understanding of patients' needs was to be aware of their own emotions:

> And it's listening to them, keeping them … safe is not the word, it's their emotions, because it is a death sentence you've just given them and they know that so it is quite hard for them to talk to you.... Even your emotions get involved because it could be your family; it could be mine, it could be anybody's. It is quite difficult. (Staff Nurse Jenkins, medical ward)

Staff Nurse Jenkins focuses on her own emotions in order to show empathy through being in touch with her inner feelings. She also reveals the dual role of professional and personal empathy and how it helps her to form a relationship with patients. Staff Nurse Krise also relates to the context of the specialist ward, stating that having patients for longer combined with being older makes 'one' more professional:

> Here [specialist ward] it is different because you are forming different relationships with your patients. Maybe it is because I am getting older as well, I am a bit more emotional as I get older. (Staff Nurse Krise, specialist ward)

However, there was another dimension to being authentic. On the one hand, some nurses and other professionals were focused on the patient's response, as represented in the quotations from Staff Nurse Jenkins and Staff Nurse Krise. However, there is an aspect of being authentic in the need for professionals to protect themselves from the patient's suffering. This pharmacist talks about the stress of managing emotions for both the personal and professional side, as professionals have to deal with emotional aspects of patients' lives throughout their illness trajectory:

> The fact that you are a nurse or a pharmacist or whatever it might be, you are a person as well. Dealing with people every single day who are having life-changing events, information, diagnosis, treatments that are changing not just their lives, but their whole family can be quite a … that sounds terrible, it's not me that is doing it, it is the person that is doing it, but it is a burden for you sometimes. It's a big, phew, and you've got to learn to cope with that as well,

> because you cannot be any support to them if you are going – 'Oh my goodness, this is terrible for you.' (Staff Nurse Scrimingeour, medical ward)

Staff Nurse Scrimingeour comments on the tension between the professional and personal interface and this is reinforced in the following quotation:

> … sometimes we are maybe so intent on protecting ourselves because we are meeting so many people, they are a different prognosis, but they are more hopeful than others, so we are trying to protect ourselves [using] a whole lot of techniques, but do we actually get to that deeper part of us and broach things, or do we hold ourselves back and say 'I'm not going there, because it is really murky almost and I can get too attached almost then.' (Staff Nurse White, specialist ward)

Staff Nurse White's quotation showcases how there are the two levels to being authentic. One is to focus on the patients' response and the other is to protect oneself. However, being familiar with the clinical needs of caring for older people with cancer may make superficial emotional engagement more evident due to a need for self-protection on the part of the nurses, who have dealt with patients' complex emotions over a long period of time. The emotional expense for professionals when engaging with patients was the potential for emotional strain[78]. It could be argued that when professionals were protecting themselves; they were perhaps more 'surface' in intent, as exemplified in the quotation of the patient Jinty, who expected an authentic response from the nurse but got one that was more 'superficial' in intent, which is more related to the professional than the patient. Professionals who are more 'surface' in intent are perhaps more likely to stereotype older patients with cancer and do not always engage in an authentic manner with patients.

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[78] Emotional strain is described as the stress caused by competing emotions at work and the tension of having to also look after yourself as a professional (Theodosius, 2008).

Reflecting on how professionals and patients make sense of managing emotions identified that the focus of care for older people with cancer is lacking due to the lack of assessment of symptoms, multimorbidity and stage of disease. The older person with cancer appears to have *more* appropriate care in the specialist ward due to the *focus of care* being seen as assessment throughout the cancer journey than an episodic admission. The current study reinforces the periods of uncertainty that this vulnerable group feel as they are hospitalized in an environment which is not resourced to consider the emotional and physical complexities. Findings showed that the specialist ward provided a safe place emotionally, where professionals described the 'ward like a home'. It could be argued that the specialist ward staff were familiar with the clinical treatment and also the patients' life world. Thus on the specialist ward there was more opportunity for reflective and authentic engagement. On the medical ward professionals seldom knew patients from a previous admission so emotional engagement was more superficial due to a lack of time and lack of understanding patients' needs.

Emotion management for patients appeared to oscillate between their multiple identities, trying to down play the impact of cancer and protecting others. The multiple identities represented by patients included a spectrum of *societal perception of being old*, and so death is inevitable to the *patients' life world* of having experienced previous losses and illness. In between this range of emotions was the 'communicative interactive stance'. Older people with cancer tended to appeal to professionals' views (see 'Trust' p. 146).

However, nurses who were pivotal in this emotional management were exercised by 'professional etiquette' while dealing with more authentic emotions for patients. While authenticity reduced the stereotyping of patients, being educated in how to be

professionally competent and reflective is central to delivering authentic care. While this section has considered the importance of authenticity there were professional challenges in managing emotions which related to clinical and personal expectations of patients. A process which helped professionals to be authentic was to appreciate that patients may settle for feeling better rather than a cure:

> Some of the problems older people have, whether it's a pain or shortness of breath, if you can even make that a bit better for them and they are able to go out and potter about in the garden or go to the shops for the paper, that's huge for me because you have actually made their life that much easier. (CNS Fenton, Lung)

The quote above recognizes both the medical and social construction of illness. Some professionals had insight into this group of patients, acknowledging that management of realistic expectations is a complex and highly skilled intervention. Professionals acknowledged that managing life plans was a *'balancing act',* where they were continually assessing and readying themselves to seize the right opportunity to talk through their emotions:

> And to give people hope, you try to give people hope but you don't want them to be too 'Well, this is going to cure me.' It is finding that balance. You don't want them to think that after this I'll be cured. It is a balancing act. (Staff Nurse Jeana, medical ward)

Gauging the right time to talk with patients demonstrated a 'balancing act' of trying to find 'middle ground' between what is professionally correct and what is best for the patient. This quote echoes the codes visited in the last chapter in relation to end of life issues and how professionals try to determine how to truth-tell within emotional engagement, which is not 'superficial' in intent, but reflective.

Truth-telling seemed to be difficult for two main reasons. Firstly, patients appeared to be seen as vulnerable and as needing to be protected and secondly, doctors did not readily stop treatment for those in the palliative care stages, according to professional accounts in the specialist ward. The psychosocial aspects of entering the palliative care stages were seen as a clinical transitional period where patients' drugs were rationalized or chemotherapy was stopped. Alternative treatments within the context of 'continuous palliation' were not discussed. The next section will discuss how professionals managed end of life issues, considering the focus of care and strategies employed to ensure that patients' life plans were being met.

Managing end of life issues

A challenge for professionals was when patients did not want further care interventions and wanted to die. Alexander was in the palliative care stages and talked about giving up, wanting professionals to help him. On reflection, Alexander may have been depressed, but it seemed professionals felt uncomfortable, as seeing the patient wanting to die as emotionally challenging:

> I got one or two pals in here; they are all cancer people, like, you're here to die. The doctor explained to me, 'We cannot give you anything to kill you.' ... I know I've got to go some day. But they say, 'You've got to live.' But I don't want to. (Alexander, prostate cancer, medical ward)

The quotation above indicates the need for giving appropriate care to older patients. There are clinical tensions in giving a patient the appropriate palliative care and addressing concerns. While Alexander enjoyed being with fellow patients, he found that his helpless situation could not be resolved as a result of his continuing pain. He saw his fellow

patients around him as dying, but could do nothing about this situation. The professional involved was also helpless, finding it difficult to seek the emotional resources required to care for a particular patient. Another quotation is given below relating to an older lady who was dying:

> She was really unwell … in pain. I knew she was going to die but was not sure if she knew. I couldn't tell her … I didn't want to make her feel worse … just let her be … but maybe I was wrong…. (Staff Nurse Scrimingeour, medical ward)

Reflective emotion management and 'professional etiquette' are highlighted here in saying the right thing and doing the right thing. Professionals felt if they spoke the truth then some patients would 'give up and turn their face to the wall'. Another fear of some professionals was giving inaccurate information to patients. This also appeared to be more likely if they were in a side room.

The therapeutic tension of truth telling was twofold, due to not knowing the truth *and* also the collegial tension between nurse and doctor. The issue of giving hope through chemotherapy was also a challenge for some professionals. Health care professionals seemed to think they had the necessary knowledge as to what patients wanted without having more of a partnership with them. Some patients did not always want chemotherapy. Implicit in the above quotation is the paternalistic attitude of professionals, which indicates a power balance in the treatment plans. Professionals may also use paternalism as a way of hindering emotional engagement, which may lead to emotional strain. 'Professional etiquette' appeared to influence the way truth was delivered. *Reflection* influenced how professionals contemplated practice. While findings have considered the tension in meeting expectations, it was also observed that through the

nurses *being there* patients had an opportunity to work through their expectations. This will be discussed in the next section.

'Being there': the nurses' role in emotion management

Specific professionals had different perspectives on care. For example, the pharmacist on the medical ward related her input to care through rationalizing medication, while the pharmacist on the specialist ward dispensed and delivered chemotherapy for patients. Some roles were thus less interactive with patients than others and, therefore, some professionals' emotional engagement were more medicalized than others. Nurses seemed to have more of an opportunity to appeal to the person side of the patient which is significant especially as older patients tend to present late:

> Older patients come in and they present late … they can't get radiotherapy and chemotherapy. You just make the time … [more time to] sit down and ask what they really want. (Staff Nurse Jones, medical ward)

Findings from the previous chapter established that an important issue for most professionals is to have the required resources (education, time and communication skills) to deal with people's emotions in knowing what to say and when. Themes such as 'taking a sideways view' and listening were examples of the processes involved in emotional engagement. The example below relates to breaking bad news and the time that is needed to give holistic care:

> You have to give them hope or else they give up … hope is the means to having something to live for; it is individual, looking to all their needs. (Staff Nurse Jones, medical ward)

> Depending on how the person is, I think if they [a health care professional] were a worrier or thought about it too much, 'Don't even bother coming into oncology.' [Humour, as she laughed.] I think it would just be 'Be prepared for, you know, emotions you know, a lot of dead and dying.' At the same time, there are a lot of good things too, different, it is different on the wards because you don't always see the positive stories, but you do sometimes. You do make people better you know. (Staff Nurse Gamlin, haematology ward)

The first quote from Staff Nurse Jones is in itself significant in that it relates to the importance of realistic expectations. Staff Nurse Gamlin highlighted the importance of reflection in exercising the need to stay strong, dealing with the risk of feeling emotional while managing expectations at end of life. In sum, emotional management is concerned with focusing on meeting patients' expectations while also reflecting on how the personal self is coping as a professional. The next section will discuss how professionals tried to engage emotionally through social skills and reflecting on their education.

Emotional engagement

The previous section on 'Education and experience' on page 171 established that having post-registration experience in education associated with cancer and palliative care enabled professionals to better understand the nature of cancer and palliative care. From a cancer and palliative care perspective, education could have improved the emotional engagement with patients in *three* ways. *Firstly,* seeing cancer as less of a frightening word allowed nurses to consider other options for treatment and to better manage symptoms. *Secondly,* education facilitated professionals' ability to approach patients. It could be suggested that if professionals learnt to manage emotions then it would reduce feelings of being superficial to patients. *Thirdly,* education prepared nurses for emotional

engagement through emphasizing the role of care delivery being essential in generating a therapeutic relationship.

Social engagement could be argued as being particularly important with the participants as they were going through changes and losses over a short period of time. In the medical ward they were going to their next place of care. Thus to understand their emotions was essential so that life plans could be made.

Previous sections such as ‘Being with and comparing to others’, ‘Trust’ and ‘Familiarity’ explored the notion of social connections with others. Along with the sharing of emotions, there was also ‘social chatting’ between patients and professionals. Mary discussed the laughter she shared with the charge nurse on the ward. Staff Nurse Jones also discussed how she would laugh with a patient at her story of afternoon tea and champagne. Findings indicate that patients *and* professionals use their *personal experience* to understand and manage cancer, thus recognizing the personal and social dimensions of personhood. Professionals, particularly nurses, invoke these deeper feelings to empathize with patients, using their own past experiences of cancer to deal with patients’ emotions. Reflection was important in understanding how professionals deal with patients’ emotions.

In many of the transcripts, professionals who were more experienced seemed to feel at ease and saw the benefit of ‘social chatting’ with patients. Older patients were noted in the findings as enjoying talking about ‘other aspects’ of their life, and therefore placing their illness within the greater life course they are experiencing. An example of understanding the psychosocial aspects of a person is given in the quote below:

> I think talking about being involved with dogs, because that way you know a little bit about me, and you are talking about something that is not too personal but they could identify with it. It turned out he was a massive Rangers supporter. I go to Ibrox. [Laughter is heard from all in the focus group]. Instant rapport, everybody interested, he's a Rangers supporter and it was just that connection, it made it much easier. (Staff Nurse Jenkins, specialist ward)

It seemed that mutuality also generated a sense of knowing the patient and being able to see the person behind the 'older cancer patient'. Thus, mutuality provided a source for understanding the moral issues which patients face:

> It is not necessarily about tackling the bigger issue, the whole big issue of diagnosis but taking it sideways, from an angle. Everybody has different views on how the older person with cancer should be treated and some people are just cruel to try and put them through treatment and things like that; and generally it depends very much on the patient, their attitude. If they want and feel that they are at peace and are accepting of their diagnosis, who are we to try and change that? But certainly with the ones we see, there is an issue. (Staff Nurse White, medical ward)

Some less experienced professionals felt that chatting with patients could lead to more sensitive issues which they might find hard to deal with. However, experienced professionals felt more comfortable with this therapeutic opportunity. Direct caregiving, assisting with physical needs, allows the opportunity for therapeutic relationships to develop.

> It's sitting with them or taking them to the toilet, and they say, 'I want to give up. And I say, 'Why do you say that?'… Just being there … we would not have that opportunity otherwise. (Staff Nurse Krise, medical ward)

Staff whose remit does not encompass direct care appeared to have fewer therapeutic opportunities. Examples of this were the pharmacist on the specialist ward or the dietician.

Also, nurses spent more time with patients. Physical proximity and increased time between patient and professionals emphasizes the uniqueness of the being with that person. The very nature of washing patients and helping them to the toilet (and other examples of physical care) was recognized by some nurses as generating a therapeutic relationship rather than a task.

As identified in the previous chapter and in Appendix L, patients had multimorbidity and symptoms which reinforced the need for holistic assessment. Physically patients found it difficult to achieve activities of living. Professionals noted that holistic assessment of patients could be carried out through physical contact. When nurses care for patients, particularly in physical ways, they give them privacy (to some extent) through drawing the curtains or shutting the door, thus allowing more true feelings to be generated between patient and professional than if they did not have privacy.

This study identifies the importance of generating social skills to enable the sharing of emotions. Findings discussed that the social skills for emotional engagement include ‘being with’ patients and ‘having a laugh’. This may be seen as superficial but led to more authentic engagement as familiarity and trust were gained.

Findings in this study indicate that professionals have a diverse range of emotional skills to care for patients. From a ward environment perspective, giving direct care to patients serves as a great opportunity to engage with patients. The sharing of emotions is particularly relevant, as patients are in the palliative care stages of their illness and the expression of their needs is essential for generating a plan for the next stage in their lives.

This *social transmission of information and knowledge* is essential towards acknowledging that caring is a social activity that creates shared meaning between patient and professional. The communication that is generated through physical interaction is beneficial in two ways. Firstly, getting to know the patient through hearing directly generates a deeper understanding of the patient. Secondly, the social process within nursing is key and particular to the ward setting. The current study explores that to be socially aware of emotions it is important to involve ourselves in the *process* of emotions, which conveys feelings to the individual that professionals are there. Creating a forum for emotional engagement is complex, as it involves a newly grasped reality on the template of prior expectations, rethinking assumptions relating to a patient. The social factors when caring for the older person with cancer include reflecting on myths and understanding about clinical expectations for the older person with cancer appealing to the person's life world. Professional education for older people with cancer reflects the need to practise patient-centred skills, such as managing patients' emotions.

Discussion

Findings in relation to the research questions

The main themes generated from the findings are related to the research questions in Table 13 below:

Table 13: Research questions and findings

How do these two settings (medical ward and specialist ward) shape:

Research questions	**Description of main findings**
• The older patients' and professionals' views on diagnosis and care delivery?	Older people tended to look to their past lives to make sense of the present. Older people also attend to the cultural norms of being stoical or appeal to their gender when discussing their roles in the home or at work. Patients liked to be with others who had the same illness thus having support from fellow patients helps patients make sense of their illness. The high occupancy of cancer patients and seeing familiar people was more prevalent in the specialist ward. This attribute added to the 'therapeutic milieu' of the ward.
• The professional roles and responses to care delivery?	Professionals used etiquette as an emotional regulation when not knowing what to say to patients and also to protect themselves from not getting too involved. However professionals also engaged in an authenticity. Trust, familiarity and knowing patients from before reinforced this authenticity but in the specialist ward there was also the issue of getting too close. Being authentic appeared to reduce stereotyping older people with cancer.
• The psychosocial experiences of older patients?	Patients in both wards presented with comorbidities and symptoms. Symptomatic relief made making clear plans for their future. Patients appealed to gender related identity which gave an example that cancer was not the only identity but rather their identity was multi-faceted. Professionals tended to see patients as older and/or had cancer.

• The interpersonal dealings between patients and professionals?	There were challenges for professionals as they navigated between regulations and emotional responses to older people with cancer. The 'in vivo' code 'etiquette' illustrated a 'filter' governing professional rules, reactions and responses to older people with cancer. Some professionals conveyed emotions to patients with varying amounts of 'professional regulation'. Some responses were more emotionally engaging with patients than others. It could be argued that being authentic reduced social stereotyping, but also how 'emotional etiquette' protects professionals from 'getting too involved'. The professionals on the specialist ward expressed more authentic and reflective emotions than the professionals on the medical ward, who were more 'superficial' in their display of emotions (due to the fast pace and lack of familiarity with patients).

Nurses were pivotal in the management of care delivery; however, organizational factors within the ward affected how nurses could totally engage emotionally with patients. The attributes of *familiarity* and *trust* were seminal to patients feeling that the ward was a safe place in an emotional and physical sense. Patients focused on their *past and present illness* to manage their emotions, thus intertwining their past in contributing to their present understanding of illness. Patients tended to also see themselves not as unitary but as part of their family, thus having a duty of protecting their family members. Patients appealed to their greater social identity of being a man or a woman or to reinforce the family norms in amongst their illness, while professionals tended to see their 'clinical cancer journey' as their initial focus. It could be argued in the current study that having cancer *with* existing multimorbidity added to the challenges of a *'master status'*. However, familiarity of

knowing professionals may have increased that possibility of being seen as *a person* rather than an older person with complex needs. In the medical ward, patients were often going to another ward setting where another set of negotiations for identity would begin. However, in most participants this addressing of their identity may be their penultimate as they reach the end stages of life. Findings from the previous chapter indicated that cancer, palliative care and gerontology have competing priorities for professionals, determining whether they focus on the cancer patient or the older patient with cancer. The role of their biography appears to be obscured within these competing identities. To further complicate this, the organization portrays a system of health care which, in imposing command over patients, lessens the focus on life worlds and clouds the patients' emotions.

As discussed in the previous chapter, when the system becomes more dominant, the recognition of patients' individual needs and their emotional discourse is lessened or diminished due to the pressure of greater organizational needs, leaving the patient feeling alienated and unable to discuss emotions. However, despite not always being able to express emotions with professionals, patients found opportunistic conversations with fellow patients to help share their feelings. It is argued that the process of *social comparison* from the norm to disruption helped locate their identity. The current study supports this finding and highlights the significance of being 'in the same boat' as other patients. Participants made use of their *past lives* to make sense of their present condition: past illness and losses were intertwined. Being hospitalized served as an emotional context, giving rise to feelings of uncertainty at times, as patients had to make sense of options and understand what was being said. Patients related to past lives while making sense of the physical transitions in hospital, reflecting on their current social and clinical

identities. The current study highlights that older patients tended to manage their lives in the ‘now’. This was particularly relevant to patients in this study who were in the palliative care stages and realized the importance of embracing the present and the importance of social interaction.

The wards were seen as *emotional places* irrespective of the type of care they offered. The current study further progresses the notion that social manifestations of emotion work through interaction. Findings also indicate that having familiarity with and being able to trust professionals helps to support patients as they process their past and present biography. The social and psychosocial impact of being older, multimorbidity, coping with physical and emotional transitions, was an ongoing process. The need for trust and familiarity with professionals was essential for patients. During the multiple changes patients derive comfort from the social situation. The ward ‘as a halfway house’ identified that patients felt ‘safe’ being in hospital in a greater social sense. However, another aspect of being safe was not only to feel professionals were familiar, but also to understand information and make choices. Some patients wanted more of an equal partnership (Mary and Jinty). Table 14 highlights the findings which appeared either to promote or inhibit emotion management:

Table 14: Factors affecting emotion management

Hindering the management of emotions	Helping emotion management
• Pain (total). • No known destination of care. • Acute admissions. • Symptoms; pain, breathlessness. • Not understanding information. • A lack of trust for others. • A lack of familiarity. • A focus of care was not congruous to patients' needs. • Prognostic uncertainty (a fear of the unknown). • Unable to 'connect' with staff. • Being seen as a label – older person with cancer.	• Being symptom-free. • Knowing the same staff. • Being listened to. • Receiving information. • Looking to their past and present experiences of life (death of a loved one). • Comparing themselves to others on the ward. • Social integration and authentic engagement from staff. • The ability to protect the family.

Attributes of the past included their gender-related roles with family members. Some patients believed they 'had to be strong' for their family and demonstrated controlled emotions ('You just have to fight it.' Or 'the children must not know'). This study further provides the illustration that patient participants undertook emotion work through using their multiple identities to manage their own illness and to manage others. This gender identity is used in their role as a mother, father, and/or grandparent to embody emotions.

To help the clinical and psychosocial ‘safety’ of patients, professionals used a professional etiquette which acted as a filter to manage information and to deal with moral issues that were important to care and to give appropriate information while not getting too emotionally involved. The current study acknowledges the notion that nurses can have the opportunity to emotionally engage with patients through attendance to the physical aspects of care. However, as identified in the previous chapter, it is the aspect of repeated admissions and getting to know the patient that generates this therapeutic relationship.

There was an ongoing balance of gauging emotions through *professional etiquette*. Also, when nurses are emotionally engaged themselves, they appear to reflect on their own experiences to help them engage with patients. In this study, it was clear that out of all the professionals, nurses were the ones that worked the hardest at ‘emotion engagement’ in two ways that were different from others. Firstly, they spent the most time with patients. Secondly, they generated an emotional attachment, perceiving patients were like family while also remembering different aspects of etiquette (informational, emotional involvement and moral duty).

Giving direct care was augmented when nurses were *emotionally engaged* with the patient. Emotional engagement was made using the following strategies in Table 15. The quotations reflect the types of emotional strategies. Professional etiquette appears to be a ‘risk’ filter by allowing professionals the time to reflect and ‘take stock’ on the implications of what they say to patients:

Table 15: Variance of engagement and type of emotional strategy

Quotations	**Type of emotional strategy**
'It could be your mum and dad.' (s)	Reflective
How do you say this to the man? (m)	Reflective
Keep stum about it. (m)	Moral attributes and being reflective
You don't want to get it wrong. (m)	Moral attributes and being reflective
They are like family to us. (s)	Authentic
It's hard not to let go sometimes. (s)	Authentic
Part of being a good nurse is showing your true self. (s)	Authentic
s=specialist ward.	
m=medical ward.	

Tensions arose when nurses could not be totally emotionally engaged with patients because they were focusing on other duties and demands that had to be carried out. It appeared that nurses, in particular, cared in a way which differed from other professionals. The attributes of time and 'being with' patients fostered an emotional bond between nurses and older people with cancer.

The current study indicates that the sharing of emotions is not mechanistic in nature but combines professional etiquette with the use of various emotions through social engagement between two people. This study reinforces the need for nurses to continually evaluate engagement with the patient and use of 'superficial', 'reflective' and 'authentic' emotions to ensure that *holistic*, effective care is given. Evaluation within these aspects of

emotional engagement would enable professionals to protect themselves through being authentic while looking to the informational, emotional and moral aspects of care delivery.

It could be argued that being authentic reduced social stereotyping, but also how 'professional etiquette' protects professionals from 'getting too involved'. The professionals on the specialist ward expressed more authentic and reflective emotions than the professionals on the medical ward, who were more 'superficial' in their display of emotions (due to the fast pace and lack of familiarity with patients). This suggests that being more involved with patients on the specialist ward created more of a challenge impacting on the professional as a person.

In sum, caring for older patients with cancer can be complex, especially due to the contextual pressures within the two wards, one with all patients with cancer where professionals often feel a great emotional attachment, while other nurses may not feel equipped to care. Emotional engagement is an essential part of nursing that enables caring behaviour and allows nurses to achieve congruence between actions and feelings with patients while also protecting themselves. It has been emphasized that there needs to be a culture in the ward settings which facilitates a more authentic presence with patients. Identifying shared professional values towards the older person with cancer, such as encouraging active learning in and from practice, identifying what emotional strategy is being used by nurses would create a more person-centred culture.

Direct care allows the opportunity for intimate relationships to develop. Thus the code of the 'halfway house' is helpful in defining if patients feel their emotions are dealt with fully or if their needs have only been dealt with in part. The current study also identifies that to

be a professional, there are central aspects to maintaining professionalism and emotional engagement.

Findings identify the challenges that professionals face in caring for patients in ward settings, which are not always conducive to emotional engagement. It is proposed that the ward should not just be an alternative place of care when patients are unable to cope at home, but an emotional space. Findings demonstrate that the ward setting goes beyond the physical necessities but relates more to the importance of how patients manage their emotions and the significance of emotional engagement.

Kelly et al.'s (2004) study, exploring the care of adolescent people with cancer, found it beneficial for patients to be in the same ward with familiar professionals and fellow patients. Caring for a particular age group over time was helpful for patients, being in 'the same boat' creating a supportive culture which he termed as a 'therapeutic milieu'. This study was helpful in concurring with findings in the present study, especially relating to the specialist ward where there was a familiarity and trust generated between patients and professionals (see sections on 'Trust' p. 146 and 'Familiarity', p. 151).

Findings demonstrated that older patients appeared to manage the diagnosis of cancer and see this as an embodiment of themselves in amongst their other identities. This has been highlighted in other studies which explore the emotional responses to coping with cancer in old age (Bellizzi and Blank, 2007; Hurria and Lichtman, 2008). The current study highlights that older patients manage their lives in the 'now' while also looking at their past – thus their past adds to how they perceive the present. This was particularly relevant to patients in this study who were in the palliative care stages and realized the importance

of embracing the present and the importance of *social interaction*. The wards were seen as emotional places, irrespective of the type of care they offered. The intimate sharing of information within an alien ward environment can make patients vulnerable. This was further augmented as patients in the study were symptomatic and thus more vulnerable.

Emotion management as a coping strategy has been identified in other studies (Sinding et al., 2005; Thomé et al., 2004a, b) as patients accept their illness and cope with cancer as an ongoing process (Hallberg, 2004; Esbensen et al., 2008). A literature review was carried out to explore older patients' understanding of death and dying. Findings revealed the readiness of older people to talk about death, revealing the heterogeneity of adaptations (Hallberg, 2004). The idea that older patients take a more submissive stance on their illness is supported in another study, Bungay and Cappello (2009). Bungay and Cappello's (2009) study explored the information and support needs of men aged 75 and over with a diagnosis of prostate cancer. Their findings demonstrated that patients often faced challenges in finding out more about their illness because of their beliefs about ageing and the overall trust they had in professionals. This current study adds to these findings, as it gives added information into the *social processes* surrounding the challenges and promotes dealing with the emotional meaning of trust as therapeutic relationships are generated between staff and patients. Patients' accounts convey the unique way they deal with emotions by looking to their past life course and perceiving cancer as less of a disruption, at times, from an emotional perspective as they look to their past lives while protecting their families.

The social context of 'being older' also has an influence on attitudes to illness, drawing upon societal beliefs and subsequent meanings attached to their particular life course.

However, the physical manifestations of their illness caused uncertainty. Charmaz (1987, 1995, 2002) focused on uncertainty as a defining factor relating to the sense of bewilderment in not understanding the nature of their illness.

Corbin and Strauss's (1992) intertwinement of the physical and biographical is helpful in understanding personhood. The 'physical' in Corbin and Strauss's terms also refers to the active work (as against a passive response) engaged in by the patient when undergoing clinical treatment, secondly the 'biographical', which is the attempt by the patient to reconnect their life prior to diagnosis with the present and future. This notion of combining an active response with biographical discourse is important in understanding the social and clinical aspects of patients' lives. Esbensen et al. (2008) interviewed sixteen older people with cancer who attended an outpatient clinic in Copenhagen. Findings described three essences of having a diagnosis of cancer. These were 'illness as a turning point marking old age', 'disturbing the family balance' and 'life and death becoming apparent'. These essences were manifested through issues such as being a patient, living with symptoms, and managing family emotions. Similarly in this current study, findings highlighted the social and clinical adaptations in patients' lives.

A significant finding was that some patients were withdrawing from social reality, almost withdrawing from life. Exley (1999a, 1999b) reinforces that death is often the result of a chronic illness and death is often foreseen or predicted. She makes the useful distinction of 'social death' before the actual death. This current study appears to reinforce this social death, but in two ways: one being from the perception of being older, and the other from having cancer. In addition, findings demonstrated that older patients appeared to manage the diagnosis of cancer and see this as an embodiment of themselves in amongst their

other identities. This has been highlighted in other studies which explore the psychoadaptive responses to coping with cancer in old age (Bellizzi and Blank, 2007; Hurria and Lichtman, 2008). Exley and Letherby (2001) described that the self is understood by the way one's biography shapes one's life. However, having a diagnosis or illness can result in the label of diagnosis being one's 'master status'.

Exley and Letherby (2001) also stated in their study that the patients who were living with terminal cancer and women with infertility and/or 'involuntary childless' undertook an 'emotion work' to manage their own emotions and also protect themselves. Exley and Letherby's (2001) study was important in detailing the importance of managing and reconstructing identities.

Emotional management in health care is more complex than, say, a commercial industry such as the work of flight attendants, which is discussed in the seminal work of Hochschild (1983) who explored 'emotion work'[79]. The examples of emotional care by nurses that go above and beyond the call of duty in this study demonstrate authentic caring.

Bolton (2000) critiqued the nature of emotional labour and stated that nurses played a special role through providing a 'gift' for patients, which was caring through unconditional giving. Aldridge (1994) also notes how nursing emphasizes a holistic relationship between nurse and patient. She also contested that emotional labour is regulated by the labour process of the ward, and being receptive towards the patients' feelings is more an emotional

[79] 'Emotion work' is the term used to describe the regulating and managing of other people's feelings (Hochschild, 1983; Exley and Letherby, 2001).

engagement. This current study reinforces that the ward characteristics influence the therapeutic relationship.

The concept of ‘emotion work’ demonstrates the tension for people in trying to deal with other people’s emotions while managing their own. This study differs from Hochschild’s study in that the context of the ward as an organizational structure is considered a place that engenders emotions, particularly in the way the environment is laid out (such as considering where patients are placed). Doctors and other staff engaging with patients on ward rounds could be argued as being more distant in care delivery than the nursing staff. This could be due to the competing priorities in care delivery. There appeared to be a social discourse within both ward settings that dominates care decisions to a lesser or greater degree. This creates a moral ‘rhetoric’ that underpins care delivery (Kleinman and Fine, 1979).

The current study takes a clinical and social approach, focusing unique coping properties of the older person with cancer. This study differs from previous research studies, which considered coping strategies of the older person with cancer outwith the hospital context (Hubbard et al., 2010; Pieters and Heilemann, 2011; Pieters et al., 2011; Sinding and Wiernikowski, 2008). Exploring the characteristics of a clinical setting highlights:

- The importance of clarity of roles and the values which embody emotional engagement.
- The importance of ‘emotion work’ as a process which both nurses and patients undertake to manage their feelings and to protect themselves.

- Recognition of the need for skills and education to enable care delivery to older people with cancer.

The next chapter concludes the thesis. It considers the extent to which aims and objectives of the study were met, and summarizes the main findings of the study in relation to the main concepts: the caring environment and emotion management. It discusses the strengths and limitations of the study. Finally, recommendations for further research will be given.

CHAPTER SIX

Discussions and Recommendations for Practice

Introduction

This chapter will be organized in two sections. The first section will discuss the findings of the study using two main topics; *care environment* and *emotion management*, integrating the literature and emphasizing what the findings add to the current body of research. Study weaknesses and strengths will also be debated. The second section will discuss further research, practice development, education and policy implications for practice.

Care environment

This study considered the contextual nature of the care environments, the *interactive stance* between patients and professionals and the impact on person-centredness. Findings identified competing societal and individual perceptions within the *care environment* which enabled the individual to be seen to a greater or lesser extent as both a unique human being with value and identity, life experience and life plans that matter, but who may also be vulnerable in health care contexts. This section will discuss the *focus of care* and *the transition to palliative care*.

Key findings are that the *focus of care* on *both* wards was not congruous to the older person with cancer, in the sense that both wards were not truly appropriate for the needs of

patients who are over 65 with a diagnosis of cancer. The focus of care was acute and/or supportive relating to the *specialty* of the ward (see page 140). While this met patients' needs in part there was little recognition of gerontology, geriatric medicine and oncology. The gero-oncology concept was not applied as a focus of care in the care environments. As a result, patients' physical and emotional needs were often unresolved due to pluralistic foci of care. The characteristics of the care environments (p. 135) and professional roles created an 'idio-culture' which created a tension of competing priorities. This resulted in care environments being a 'halfway house' in an emotional and/or physical sense depending on the specialty, intent of care and interactions with patients.

Findings indicated that education in cancer care improved how nurses provided holistic support being able to assess their clinical and emotional needs (page 171). The importance for older patients with cancer being cared for by the appropriate professionals in the appropriate setting who are educated in cancer has been recognized in other studies (Butow et al., 2012; Foster et al., 2010)[80]. Some studies were seminal in justifying this study particularly considering the care in two ward settings and the need for education in palliative care (Chouliara et al., 2004a; Hockley et al., 2005; Froggatt, 2000b).

These studies reinforced findings from this current study, placing importance on the role of the nurse and the appropriate place of care. Chouliara et al.'s study (2004a) reinforced the findings that the specialist ward was preferable to a non-cancer ward. Hockley et al. (2005) explored palliative care for cancer and non-cancer patients (centring on the last

[80] This is significant considering that there is an increase of patients with cancer as patients are living longer and will be cared for in the hospital setting (Department of Health, 2012a, 2012b; Scottish Government, 2008a).

days of life) in care homes. Using action research Hockley et al. (2005) presented findings relating to challenges in care giving at end of life ascertaining that the context of care and specialty was significant in determining how care was provided. Hockley et al. (2005) reinforced the importance in education in palliative care, appropriate referral of clinical nurse specialists and collaboration, especially in the care setting which is not specialist. This was helpful in that the study looked at *how* nurses cared for older patients at the palliative care stages.

While Hockley et al.'s study (2005) emphasized the importance of the focus of care which was congruous to patients' needs, there was little insight into the contextual nature of care, such as the importance of time with the same patient, repeated admissions to the same ward. These attributes are important for generating *familiarity* between patients and professionals facilitating authenticity in care environments.

Froggatt (2000b) carried out a palliative care educational project, evaluating the effect on palliative care delivery in care homes. This study was helpful in that it indicated that while education in palliative care is needed there needs to be a culture change within the ward to help integrate education into practice.

This current study has acknowledged that there needs to be consideration of how the therapeutic relationship is generated within diverse settings. In addition, there needs to be more education for nurses in *palliative care* but also *cancer, gerontology and care of the older person* to ensure a holistic appreciation of patients' unmet needs and to engender a person-centred approach for this heterogeneous group. Combining *education* and an understanding of the importance of the *therapeutic interaction* is essential.

Other studies and models (relating to the older person or in the care setting) provide knowledge into the therapeutic relationship and the importance of knowing the patient have also been helpful (McCormack and McCance, 2010; Nolan et al., 2001a, 2001b; Malone, 2003). These authors all reinforce the notion of 'being with' through creating an approach to care which involves a sense of continuity, and a sense of knowing (Nolan et al., 2001a, 2001b). Malone (2003) explored the notion of 'proximal' nursing focusing on the importance of 'being with' through direct care giving. Nolan et al. (2001a, 2001b) also placed importance of 'being with' through the senses framework. The Nolan et al. (2006) framework involves a set of principles which include the goal of maintaining the dignity of older people, enabling them to be seen as people[81]. These studies were helpful in highlighting the importance of interaction and direct care.

This current study reinforced the role of the nurse in establishing patient needs through therapeutic interaction and listening to experiences. Giving *direct care*[82] helped the therapeutic relationship in three ways. Firstly, it generated a social relationship. Secondly, it enabled patients to have an active participation in their care (see theme 'active participation' on p. 149). Thirdly, giving direct care ensures that there was emotional engagement, ensuring the ward was a 'halfway house' in an emotional and physical sense.

The present study also highlighted that when the wards commonly relate to a particular focus of care with each ward having their own medical team there is little collaboration

[81] A similar model is proposed by Hart et al. (2003), who ask that professionals develop their thinking so as to promote the needs of disadvantaged groups of patients. As this model was not developed specifically with reference to the older person, it was not selected as the central framework around which to base analysis and recommendations.

[82] Direct care means giving physical care to the patient such as helping with activities of living.

with other cancer, palliative care or gerontology specialists. In addition, being in a cancer unit, there was less access to cancer and older person specialists. There was also little partnership with patients due to the greater organizational demands (especially in the medical ward). Puts et al. (2010) focused their study on cancer specialists and geriatricians highlighting the difficulties in collaboration between specialties and the lack of communication relating to coordination of patients' care.

This current study also gave insight into the challenges of assessment such as the lack of collaboration with clinical nurse specialists or the recognition of palliative care needs due to the lack of appropriate focus of care. Importantly, in both wards, nurses were pivotal in the care delivery managing organizational demands while trying to meet the patients' needs through direct care.

Collaboration and assessment is essential in recognizing complexities of comorbidities, symptoms and the *transition to palliative care*. The need to have a nurse who assesses symptoms and understands the patients' needs through a therapeutic relationship is supported by the current study.

The need for assessment and collaboration has been recognized in many other studies (Chouliara et al., 2004a; Puts et al., 2010; Extermann and Hurria, 2007) and in key political documents (Scottish Government, 2007, 2008a, 2008b, 2008c). In relation to assessment Chouliara et al.'s study (2004a) associated more to the clinical measurement of comorbidities than symptom management. Hockley et al. (2005) highlighted the need for symptom management at the palliative stage of the patients' journey. While these studies and government documents were supportive of exploring assessment and decision making

in cancer care diverse settings, there was a gap in understanding the *therapeutic nature* of *how* professionals (particularly nurses) interact with older patients throughout the cancer trajectory considering site specific diseases, social and clinical needs.

This current study provided insight into the differences in care delivery considering the stage of the cancer journey and disease (e.g. patients with end stage lung cancer were all cared for in the medical ward) and how this influences patients' experiences and outcomes (patients on both wards had little access to palliative care services despite their complex symptoms). This current study also acknowledged that the remit of professionals augmented with the focus of care could challenge holistic assessment and joint decision making if not coordinated or suited to patients' needs, particularly in the transition to palliative care.

In sum, the focus of care augmented with the therapeutic relationship; *familiarity, continuity of care, education, assessment and collaboration with professionals and the patient are all essential for a person centred approach*[83]. These attributes are essential considering the need to assess how patients' experiences make life plans but also how important this is at the palliative care stages. Considering the rise in cancer in older patients and their need for care in hospital care environments, these findings are timely but also more research is needed to ensure a workforce is equipped and able to meet patients' needs (Macmillan Cancer Support, 2014). While this study established the attributes for a

[83] Appendix Q shows the themes and examples from quotes in the study which give an indication of environmental and emotional needs for patients based on the findings of this study which engender a person-centred approach.

therapeutic engagement, this study also recognized that there were specific emotional complexities for patients and professionals. This will be discussed in the next section.

Emotion management

This section will deliberate on how *emotion management* posed challenges for both patients and professionals. Patients used *past life experiences* to influence how they made sense of their illness. From a professional perspective, emotion management presented a challenge due to the complexity of organizational forces reducing the ability to take time (on the medical ward). While on the specialist ward, emotional bonds were generated with patients believing they were 'like family' while finding it difficult to convey their professionalism in breaking bad news saying 'How can you say that to a man?'

The older person told *past life experiences*, which were not chronological, representing how patients see the past and present as intertwined. The intertwining of cancer and old age meant that some patients were accepting of their illness, reinforcing expectations of the end of life. The past was very much relayed through the present, as can be seen in Janet, who still talked of her husband's death and the egg she had made for him before he died. This story was mixed in with how her parents had died, and her observation that she did not want to die like her father. Another example was Alexander, who discussed his current illness alongside his past cancer and the loss of his wife. There was also a *temporal* aspect to their accounts, as many used their past experiences to make sense of their present. This familiarity of having experiences of illness (themselves or through their family) appeared to help them make sense of their current diagnosis. This is an important finding reinforcing the significance of 'being with' patients.

This study established that listening to patients' experiences enhances the assessment of care needs and *interactions* between health care professionals and patients. The study reinforced the need to consider older patients' experiences in conjunction with their on-going lives. This study has considered how older people use their experiences when diagnosed with cancer in care settings thus reinforcing the need for 'gero-oncology'. Importantly, this current study recognized the importance of the concept of 'gero-oncology' (Kagan, 2008) placing significance on care delivery encompassing physical and emotional aspects of a 'life mostly lived'.

The stage of their cancer journey and life experience is also significant in how older patients make sense of their illness (Mary's and David's stories were very different from Janet's and Ruth's). This is important for future practice as the higher population of wards will be occupied with older people with cancer. There is a necessity to consider past illnesses, losses and experiences, to ensure appropriate life plans are made.

Acknowledging how past experiences inform older patients with cancer has been stated in other studies as a way of managing their illness (Hubbard et al., 2010; Pieters and Heilemann, 2011; Pieters et al., 2011; Sinding and Wiernikowski, 2008). Hubbard et al. (2010) considered patients with colorectal cancer, while Sinding and Wiernikowski (2008) considered people with gynaecological cancer. While finding these studies helpful in identifying a unique aspect to the experiences of older people with cancer, this current study also found benefit in 'communicative interactive stance' which is key to generating an authentic presence.

Listening to patients' narratives[84] has been fruitful in many studies used in the exploration of improving patient care (Cepeda et al., 2008; Kumagai et al., 2009; Elwyn and Gwyn, 1999; Bury, 2001). Hsu and McCormack (2011) used a problem-solution pattern framework that enabled the reconfiguring of narratives in the context of the older person's past, the here and now and the context of their usual level of well-being or ill-being.

This current study reinforced how patients also managed their emotions through 'being with and comparing to others' while protecting others' emotions. Older people with cancer within the ward settings enjoyed seeing professionals and fellow patients. This *continuity* and *social interaction* was important as it allowed patients to make sense of their illness. Through gauging other people's emotions there appeared to be a sense of comfort through a mutual understanding between patient and professional.

Duggleby et al. (2010) also found that older patients enjoyed being with others in a community hospital. The notion of being 'in the same boat' was also emphasized in Kelly et al.'s ethnographic study (2004) when exploring adolescents with cancer. This current study reinforces the importance of having a 'therapeutic mileu' augmented with patients feeling they are in the 'same boat'.

In sum, *emotion management* was an exponent theme which illustrates the processes of how patients looked at past lives and engagement with others to make sense of their illness.

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[84] Narratives (patient stories) were first introduced in the works of Frank (1995).

Findings identified that professionals were challenged by ‘professional etiquette’ and emotional engagement. Professionals restrained their emotions, believing they should try to do the right thing and not get involved. This professional etiquette reinforced the barrier to truth-telling. At the same time, patients looked to staff for the truth while protecting their families from the emotional impact. This study highlighted the fine ‘balancing act’ protecting patients and their family members and the protection between personal and the professional stances.

Nurses spoke of patients being ‘like family’, and that the ward was like their home. Conversely, professionals tried to protect themselves, they could not get as close to patients as they wanted to. The aspects of being a ‘professional’ acted as a filter for emotional engagement. Emotional engagement involved the expression of different emotions, with professionals being ‘superficial’, ‘reflective’ and/or ‘authentic’. The present study has also found that there are levels of emotion management which take place through emotional engagement. Superficial, reflective and authentic levels of engagement were all used by professionals (as outlined on page 225). The levels of emotion management appeared to be relational and context related. Findings demonstrated that:

- Superficial engagement was used when nurses did not have time or have the right information. There was also an element of emotional giving of oneself between superficial engagement and reflective engagement, as professionals reflected on their personal lives or thoughts such as ‘that could be my mum in that bed’ or you get more emotional as you get older. To be authentic, professionals needed to be reflective in how they emotionally engaged with patients.

- There were multiple identities, values and attitudes that professionals appeal to; societal beliefs about older people, myths about cancer. In addition, there were attitudes which related to paternalism perceiving older people as not wanting information or needing information due to their age.
- Authenticity in emotional engagement with patients could be said to reduce the stereotyping[85] of patients allowing the person to be seen through this 'communicative interactive stance'.

Hochschild (1983) discussed different aspects of emotional engagement (inner and surface). Reading her work gave more analytical potential for the current study. Hochschild's work is helpful in unpacking emotional strategies that people use to engage with others. This present study differs in that the findings relate to ill health, professional regulations and how the different emotional layers are used as a spectrum which is temporal in nature. Hochschild (1983) draws on different models of emotion, such as Goffman's social theory of emotion. The current study appeals to the authenticity of caring through the use of the three emotional strategies. These strategies are less from the perspective of Goffman (1959) seeing people as acting, but more *sharing* of emotion as a gift focusing on the social construction of meaning.

Theodosius (2008) compared two ward settings to explore the perception of emotional labour from nurses caring for patients (mixed ages) within two ward settings. Theodosius

[85] In October 2012 the provisions of the Equality Act (Home Office, 2010), which prohibits age discrimination, were extended to public health sector organizations. The Act applies to direct or indirect discrimination against a person because of age. It is recommended that health care providers need to ensure their delivery of services can be objectively justified to the satisfaction of a court if challenged (Home Office, 2010).

demonstrated inner and surface feelings which focus on the social psychology. This present study gave further insight into the different levels of emotional engagement. While the term 'emotional labour' conveys the notion that sharing emotions is 'hard work', James (1992) states that the term 'labour' tends to escape the sense that caring can be altruistically motivated.

The current study stresses how emotions are embodied through the communication between individuals. It was apparent that through shared emotionality with others individuals learn about their own and others' emotions. This study reinforced that emotion was therefore crucial to how people make sense of themselves and to social interaction. An important finding is that because emotion is conveyed through interaction, the shared response can change as to the emotional state of others[86].

Findings demonstrated that emotion management was a *dynamic temporal concept* which changed, based on shifting wants and expectations. This is particularly the case, since patients' diagnosis was at a point where they could be said to have 'a life mostly lived' which makes emotion management a more fragile concept as patients reflected on their end of life. There were distinct differences in how emotions were perceived, as professionals focused more on treatment and/or supportive care, while patients considered expectations relating to holism and quality of life.

There has been particular relevance made to older people (Askham, 2005; Blomberg and Sahlberg-Blom, 2007; Nolan et al., 2001a, 2001b). This current study acknowledges the

[86] This has also been recognized in other studies (Craib, 1995; Hochschild, 1979).

contextual and relational importance, especially when older patients with cancer are being cared for in care environments and focuses on the importance of biography in the transition to palliative care.

Integral to the multiple discourses involved between professionalism and emotional engagement is the essence of person-centredness through interaction. There were important differences in the ways in which person-centredness was 'processed'. Person-centredness was perceived differently by patients and professionals, and this characterizes their varying identities of personhood for the person with cancer: social, clinical treatment, symptoms, and expectations. Findings identified the value of authenticity in reinforcing emotions which ensured seeing the person behind the disease. Attributes that were important to person-centredness from this study were the following:

- The importance of emotional and physical safety.
- The significance of continuity of care.
- The requirement for familiarity between patients and professionals.
- The necessity for patients to be involved and to understand their care.
- To meet patients' expectations.
- To engender the sense of self within the patient.

Central to this study is the importance of *interacting* with others in an environment. There are several studies which reinforce that the impact of place on patients is central to the impact of patients' experiences (Andrews, 2003; McCormack and McCance, 2010). This current study focuses on the importance of professionals being authentic through reflective emotional engagement. In addition there is importance given to the concept of 'direct care', to be close in proximity which fosters authenticity.

The health care strategy for Scotland (Scottish Government, 2010) recognizes that the process of person-centred care is essentially experiential and is produced in or by interactions between patients and health care contexts. This has important implications for the context of organizations and the way patients and professionals engage in emotions. Entwistle et al. (2002, 2010) further clarify that social contexts, relationships and interactions influence how people are, and are able to be.

It is widely known that there have been poor care and compassion deficits in the NHS (Paley, 2014). This was exemplified using two major reports by Robert Francis in the UK as a point of reference. Francis enquired into the events of the Mid Staffordshire Hospital between 2005 and 2009. There was a significant national debate which was to result in changes into nurse education. The culture within the wards demonstrated 'compassion failure' interlocking social understanding with contextual factors. It is important following the Mid Staffordshire report (Department of Health, 2013) that there should be an increased focus on the culture of information giving and caring for older patients. The present study also reinforces these findings focusing on the education, values; social, clinical and emotional engagement of nurses. Findings from this study identified how acknowledging emotions of *both* patients and professionals will engender a therapeutic relationship and maintain authenticity. The next section will discuss the appropriateness of the sample, limitations and strengths of the study.

Appropriateness of the sample

The sample was not longitudinal, so the data did not generate some of the expectations or wants from patients which may have emerged as an outcome. However, this was not the

remit of the study. Further research over time to see if patients' expectations and wants were achieved would have further developed an understanding of older patients living with cancer. Although the sample was diverse, it could have included more patients at the earlier stages of their disease, as well as including other cancers and/or other professionals who may have helped gain another perspective of care. Community-based participants may have had a role to play in exploring the continuity of care[87]. The sample was also within a general hospital in the north-east of Scotland. Generating the views from other parts of the country, such as from an urban area, might have elicited different findings and recommendations. However, there is currently a gap in research using the chosen sampling strategy, thus giving support to this study.

Potential limitations of the study

This is a small study which cannot be generalizable but more transferable, generating deep knowledge relating to care delivery for the older person. Due to the theoretical underpinnings, the retrospective nature of accounts meant that participants were recounting events from the past to make sense of their current situation. Most participants taking part in interviews and focus groups had clearly not discussed some events, and so this creation of meaning was new to them. It was also evident that participants changed their views and opinions. The study was congruous with a broad social constructionist approach, meaning that there were multiple versions of the truth which were contextual.

[87] However, research has identified that the majority of cancer and palliative care occurs in hospital (Gomes and Higginson, 2006).

The sampling strategy also enabled a diversity of accounts which were analysed and further refined when the dissemination focus groups were undertaken. Accepting that the interviews were representing realities at one point in time and then returning at a later date may have shed further light on the data.

It is important in qualitative research to consider who participated and also who did not participate. For example, interviewing different grades of doctors might have given a different perspective on the medical model of assessing care and exploring the rationale for certain decisions. However, due to the ethical guidelines binding recruitment, it was not possible to source these potential participants.

Nine out of the ten patients were in the palliative care stages. It would have been more helpful to have had more patients in the active stages of treatment, especially when looking at the caring environment and emotional engagement. As a result of the sample being mostly in the palliative care stages, recommendations were not inclusive of cancer screening or rehabilitation.

No dissemination focus groups or focus groups were allowed for the patients, due to ethical issues. Including patients in focus groups might have given insight into broader constructs of being older and commonalities in the care process.

Strengths of the research

As already stated, some participants wanted to make a difference in the quality of care and had a genuine interest in the study. Others may not have thought of the interview process

as helpful to them, as it took up time in an already busy environment. The perspectives were helpful in highlighting both societal and individual perspectives to care delivery.

Exploring the care in a cancer unit had not been done before, but given substantiation for the study it has brought new knowledge relating to the focus of care, life context and multimorbidity.

The comparative potential in both the sample and care setting gave colourful data through multiple lenses. The ontological and epistemological framework allowed the exploration of multiple truths. The data generation methods were helpful in addressing the group culture 'the sum being greater than the parts' while also gaining more personal accounts. The dissemination focus groups were invaluable in not only member checking, but in adding to the perspectives of the findings.

In sum, knowledge has been gained highlighting commonalities and the different emphases accorded to issues such as societal perceptions, knowledge, expectations of care, life stage, relationships, identity, and emotion management. Establishing social and clinical tensions that arise when caring for older people with cancer has also provided insight into the attributes of 'person-centred' care.

The next section of the chapter will discuss *recommendations* for future research, practice development, education and policy.

Recommendations

Future research

There is a need for clarification of specific points made in this thesis using particular methodological approaches as part of future research. The three main focuses for future research are: assessment for the older person with cancer using the Comprehensive Geriatric Assessment (CGA[88]), exploring the value of patient experiences using patient narratives, and developing further knowledge of emotion management in nurses, using reflective diaries.

Assessment for the older person with cancer

A number of factors are thought to contribute to the high mortality of the older population with cancer such as ageism (Wagner et al., 1996; Austin and Russell, 2003; Kagan, 2008). Late presentation and diagnosis in the over-65s are prevalent, especially in rural areas (Given and Given, 2008). As discussed, there is a growing body of research which suggests that there is under-treatment, but also older patients refusing treatment.

Findings from this study clearly reflect a lack of comprehensive assessment in supportive care. Further research is needed to understand how a supportive and collaborative role for professionals in multi-disciplinary assessment could provide more appropriate focus of

[88] The International Society of Geriatric Oncology (SIOG) recommended the CGA. This is a multi-disciplinary evaluation used to assess functional age and multimorbidity that may affect cancer treatment and supportive management (Ellis et al., 2011; Extermann, 2005; Rao and Cohen, 2004). The CGA has been found to be helpful for professionals to coordinate and develop an appropriate treatment plan, as well as to guide the most supportive interventions for patients. This recommendation was also made by other bodies throughout Europe.

care (using the GCA) in other care environments. A comparative study between four wards in a cancer unit will give further insight into the benefits of interdisciplinary working and professional education. The wards would include surgical, medical, older person and a specialist cancer ward (giving a more diverse sample and setting). This would hopefully generate a breadth of sample across the cancer trajectory.

Two wards would include professionals assessing patients with the CGA; there would also be educational courses for general nurses in the non-specialist ward in cancer care and the older person. Conversely in the specialist ward, nurses would be educated in the needs of the older person. The role of specialist nurses engaging in the assessment in the CGA would also be reviewed through semi-structured interviews and focus groups. The other two wards would have no assessment or educational training. Findings would provide insight into the benefits of using the CGA and other interventions which would help to assess older patients with cancer in different clinical settings.

Patient experiences

Reflecting on patient accounts, it was apparent that patients benefited from talking about their experiences. Reading and reflecting on current literature with this study highlighted the importance of looking further into how older patients, with different cancers and stages of illness, use their life experiences to cope with their diagnosis.

Acknowledging and valuing personal biography and the skilful use of knowledge of the past in contextualizing the present and future would give more insight into understanding the older person with cancer. Discussing their experiences would promote a sense of patient significance in amongst their confusion in trying to understand professionals'

medical jargon. Having a shared sense of meaning would also generate trust and familiarity, and would enhance the therapeutic relationship. Using a more systematic communication protocol which is suited to embrace patients' stories would allow a greater understanding of their unmet needs. The use of patient interviews has great scope for reflecting patients' journeys through the hospital system, intertwined with their individual and cultural beliefs and to give deeper insight into experiences of their illness and the kinds of knowledge needed to provide effective person-centred care.

It is proposed that interviewing older people in two ward settings (surgical and medical) in a cancer unit using the data generation method of 'patient narratives'[89] would provide an option for exploring personal experiences, providing insight into treatment decisions that can help how health services can be developed and provided. Research that illustrates the benefits of patient experiences would enhance person-centredness. This approach is potentially transferable to other clinical settings, ensuring continuity not only throughout the trajectory of the patients' illness, but as a representation of continuity within their lives.

Emotion management

Findings from this study have reinforced the need for professionals to reflect on emotional engagement with patients to enhance their skills. Further research into what practice development mechanisms could be put in place to ensure reflection and authentic care is recommended. Using group discussion (debriefing report giving and completion of

[89] Patient narratives have been used as a methodology for understanding experiences of health care (Hsu and McCormack, 2011).

reflective diaries) during report times would allow exploration of challenges and promoters for authentic care. It is recognized that having a reflective diary would promote reflection in practice. Examples of some reflective questions could be:

- *What was incident?*
- *What values do I believe in?*
- *Engage in focused evaluation of reoccurring themes.*
- *Reflect on what is habitual (organizational routine).*
- *How do I need to improve the care that was delivered?*
- *Develop and appraise action taken.*

Considering the complexity of 'emotion work' which professionals undergo when dealing with sensitive issues with patients indicates that there are hidden emotional thoughts that would benefit from being shared. The sharing of emotions with other professionals is said to lead to intellectual growth through discussions and interactions with colleagues (Dewing, 2008). Using report times would also help in looking at the range of patients that are being cared for, perhaps thus ensuring there are no values placed on one patient rather than another. This would reduce the potential of ageism. Using a sample of professionals with various educational and clinical experiences would add to the diversity of the attributes that may make professionals more authentic. It is proposed that comparing reflective accounts with colleagues across two wards would be beneficial, exploring the usefulness of these approaches to enable exploration of feelings surrounding the care for the older adult with cancer.

In sum, the three research studies would provide new knowledge as to how we could enhance person-centeredness for the older person with cancer.

Practice development and education

Recommendations relate to practice development and education which would promote more effective care delivery for this group of patients. These include education for registered nurses in cancer, palliative care and gerontology, referral to palliative care (encompassing gero-oncology) the use of assessment tools, inter-professional collaboration through having a link nurse, personalized care planning and education in emotion management including the need for professionals to look after themselves.

Education in *cancer palliative care and gerontology* would help nurses to understand more clearly the ageing process, the impact of comorbidities, symptom clusters and the particular challenges in assessing older people with cancer[90]. Educating nurses in cancer and the older person particularly in 'gero-oncology' at undergraduate and post graduate level is needed to ensure professionals are fit for purpose. Kagan (2008) advocated that the biomedical model of geriatric and oncology care be replaced with the concept of gero-oncology so that the specialty of gerontology could embrace more social and psycho-adaptive domains of an older person's life.

The timely referral to *palliative care* would help ensure symptom management especially when symptom clusters were evident. This has been advised in key strategic documents (Scottish Government, 2011; Mercer et al., 2012). To ensure timely referral it would be helpful to have a 'satellite' team who are trained in cancer and the older person to visit

[90] The EONS Post-basic Curriculum for Cancer in Older People (2009) has been developed and the main aims are to provide post-basic training in six domains relating to older people; the impact of cancer on older people; decision-making and communication; and nursing assessment.

wards and to assess patients[91]. Having a clear referral process (using the appropriate assessment tool) and discussion with the multi-disciplinary team would enable a more coordinated care from the wards to home or next place of care. The benefits of having older care specialists as an active part of the cancer care team are invaluable in assessing patients and providing multi-disciplinary support (Payne, 2008)[92].

The Scottish Government (2011) recommends the tools for symptom assessment such as the Edmonton Symptom Assessment Scale and the Distress Thermometer. The use of these tools will enable the patient to *feel involved* in their care, and to feel that their expressions of the 'total experience' of symptoms are being listened to. This may also help with prognostic uncertainty and personalized care planning. In collaboration with systematic assessment it is also imperative to have clear mechanisms for referral to specialist services.

It is recommended, to ensure equity of service in the two ward settings, that there is routine use of the Comprehensive Geriatric Assessment (CGA). The assessment should be considered within different settings with the focus on geriatric and oncology. The CGA is routinely used in geriatric medicine. It is also recommended that this tool should be used in medical and specialist settings to ensure that the older patient with cancer is in the appropriate place.

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[91] This is already being done in pilot sites throughout England (Department of Health, 2011).

[92] The Cancer Patient Experience Survey 2011/2012 (Department of Health, 2012a) reported that older people are less likely than younger people to be given the name of a clinical nurse specialist, understandable written information about their treatment and illness, directed sources for financial assistance, and access to support and self-help groups. The current study reinforces these observations. Other studies have reinforced the need for holistic assessment (Department of Health, 2011).

Professionals in the specialist ward also benefited from caring for patients who were all diagnosed with cancer, since they understood their patients' needs more, due to their knowledge and experience. There is a need for education in using the CGA especially in relation to how it is used in conjunction with other assessment tools and the subsequent action plan. As the tool is commonly used in geriatric medicine, a specialist nurse from older person services could help educate fellow specialist nurses who attend different ward settings.

There is a need for timely referrals and collaboration with other professionals. This, in conjunction with familiarity and 'direct care' which is undertaken by the nurse, is essential in understanding physical and emotional needs of patients and facilitating authenticity. It is recommended that clinical assessment is used in conjunction with patients' experiences to ensure there is a mutual goal.

Collaboration of roles of nurses in both gerontology *and* cancer care would be particularly advantageous in coordinating older people's care between specialist and generalist settings and their next place of care. Creating a link nurse role between the wards that is trained in both cancer *and* care of the older person would be the appropriate person to work with the professionals on the ward to understand the patients' needs. It is important that the link nurse would attend to all patients who are older with cancer[93]. It is also recommended that education and capacity planning is made to ensure the workforce is fit for purpose to meet this need.

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[93] There is an increase in secondary cancers in older people. It is also important that professionals use transferable skills to all older people with cancer considering the lack of resources to meet people's needs.

It is recommended that a personalized care plan would enable patients to order their varied desires and concerns so that there is an ordering of priority according to their story[94]. It is also imperative that on listening to patients' experiences that the social *and* medical construct of their illness is given attention. Due to 'integrating cancer in a life mostly lived'[95], patients and staff tended to self-stereotype 'being old', believing that they were too old to live on, and that they had already experienced a good life. Therefore, listening to their experiences would reduce patients and professionals stereotyping.

While patients' life worlds were important, how older patients with cancer manage their emotions is also important. Recognizing the interface between gerontology *and* oncology is essential in recognizing the importance of patient experiences and emotion management as patients commonly managed their own feelings, often in order to protect others. Kagan (1997) makes a strong case that incorporating gerontology into cancer care will reduce professionals' perceptions of seeing older people as a homogenous group and rather encourage the perception of them as a heterogeneous group with individual experiences in a life mostly lived.

The present study reinforces the meaning of having continuity through hospital contact with professionals and patients which strengthens the opportunity to talk openly with others about their past and present experiences. Having a clear picture of patients'

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[94] Personalized care planning would reinforce this coordination of care to ensure patients' expectations. Developing a personalized care plan is central, gauging people's emotions and has been recommended in other studies (National Centre for Social Research, 2009; Nolan et al., 2006; Angus et al., 1999).

[95] 'Integrating cancer in a life mostly lived' was a term used by Kagan (2009).

experiences and how he or she makes sense of what is happening will provide a standard against which the nurse can compare current decisions and emotions of the patient.

It is recommended that professionals are taught how to manage emotions (at undergraduate and post graduate level) to help support emotions of others. Recommendations for practice are that there are more educational courses for nurses in diverse care environments to learn how to have a sympathetic presence and the importance of 'direct care' and 'being with'. This has been recommended in other studies (Connolly et al., 2010)[96]. It is proposed that professionals:

- Recognize the different levels of emotional engagement to ensure that values and attitudes are person-centred.
- Distinguish the different ways patients are assessed from a clinical (being older or having cancer), life stage or person stance and the ways we emotionally engage.
- Acknowledge the importance of authenticity when there is communication between patient and professional.

This current study underlines this message reinforcing the need to think of the different levels of emotion as well as professional etiquette which underpins the role of the nurse. While authenticity is essential it is also recommended that nurses look after themselves as professionals engage in 'emotion work'.

[96] Connelly et al., (2010) recognizes that professionals have undergone training in how to deal with fears and emotions such as SAGE & THYME.

Professionals looking after themselves

Findings indicated that staff have to be more supported in practice. This is especially important when working with older patients with cancer, with the emotional demands and strain that can impact on professional lives and themselves personally. It appeared that work stress was also related to high workload and a lack of education to care for this particular group of patients. The fact that care was within a general hospital with less contact with specialist nurses and clinical staff may also have led to problems in care delivery.

This has been noted in other studies. Morse et al. (2006) makes a differentiation based on two broad characteristics. One is being focused on the patient's response and thus being engaged. The other is protecting oneself from suffering and thus more controlled. This is similar to the current study in that nurses displayed a range of emotions, but when they were reflective they were able to look to themselves to acknowledge the increasing demands of the role and what they may want to support themselves. Lambert and Lambert (2008) also acknowledge work related stress experienced by nurses more generally. Role conflict and role ambiguity have been associated as sources of stress. Payne (2001) investigated aspects of hospice work and found high levels of emotional exhaustion and extreme depersonalisation of patients. Lambert and Lambert (2008) and Chang et al. (2007) showed that nurses found it helpful to seek social support with colleagues and to problem solve. This is also reinforced in this study.

It is also proposed that professionals reflect on their emotions having talked with patients. This is important so that focus and time is given to *how* they can improve their skills and also guard and enrich themselves from over exposure of emotion causing strain on their

performance and self. Recommendations would be that nurses ensure they use the support network of clinical supervision, and to use opportunities when the team is all together to talk about their feelings towards patients (report time may be a good opportunity). It is also recommended that professionals engage in education on 'emotional engagement' to reduce societal ageism (which occurs when professionals are not fully engaged with patients) and to protect themselves when they feel they are 'getting too involved' with patients. Education would also have a reflective component, so that nurses could evaluate their practice and learn how to manage emotions while giving authentic care to older patients with cancer.

Policy

Policy recommendations relate to every ward having personalized care planning[97] to highlight the impact that assessment on patient experiences and symptoms can have on patient experiences and outcomes. This has been reinforced by other documents (Holistic needs assessment for people with cancer: a practical guide for healthcare professionals, Department of Health, 2011). It is essential that patients can review the treatment options with current information available.

It is recommended that organizations and individuals aim to reduce cancer inequalities and to include key principles in policies surrounding assessment (such as using the CGA) and continuity of care which could be used as a helpful checklist alongside other policy

[97] Personalized care planning would allow patients' biography to be documented.

initiatives[98] relating to care for the older person with cancer. Personalized care planning augmented with assessment using the GCA will allow patients' biography to be heard which will help create a shared care plan. This plan in conjunction with the CGA will reduce inequalities in care settings and help good quality working.

Policy recommendations relate to the link nurse being part of a 'gero-oncology' task force that review older patients being admitted to cancer units and centres to ensure they are cared for in the appropriate setting with an interdisciplinary team who collaborate in decisions using systematic assessment[99].

In summary, firstly, this chapter has discussed the findings of the study using two main topics; *care environment* and *emotion management*, integrating the literature, emphasizing what the findings add to the current body of research. Study weaknesses and strengths were debated. Secondly, further research, practice development, education and policy implications for practice were debated.

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[98] See National Cancer Equality Initiative, 2009.

[99] This is of particular importance given the prospective amalgamation of health and social care in achieving health equality (Macmillan Cancer Support, 2014).

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APPENDICES

Appendix A: Databases and reasons for inclusion

Databases	**Reasons for databases**
CINAHL - 1994-October 2011	The Cumulative Index to Nursing and allied health literature is a comprehensive resource for nursing and allied health literature.
BNI - 1994-October 2011	The British Nursing Index is a UK database covering over 240 UK journals.
Medline - 1988-2011	The national Library of Medicine's database contains 18 million references covering biomedicine and health.
EMBASE - 1996-2011	This database covers 7,000 journals taken from biomedical and pharmaceutical citations.
Psyc INFO - 1996-2011	This database has 3 million records devoted to peer-reviewed literature in the behavioural sciences and mental health.
TRIP - 1997-2011	This database started in 1997, which includes professional systematic reviews and international guidelines.

Appendix B: Extract of charting process from 6 retrieved studies

Study	**Themes**	**Country**	**Aim of study**	**Sample**	**Design**	**Findings**
Bain and Campbell 2000.	Patients' perspectives of care (rural versus urban).	Scotland	Rural and urban experiences of care (access and information). Examine priorities and experiences of care.	32 22 cancer patients (aged 60 to 70 plus years) and 10 spouses.	Focus groups.	Patients from rural areas were less inquisitive about their care than patients from the urban setting. There was also less speed of referral to specialists.
Sahay et al. 2000.	Patients' perspectives of care (post-treatment).	Toronto	Experiences of care from health care professionals	20 patients (48-87 years).	Interviews by telephone.	Patients who were older were happy with care especially from specialists. They wanted information about treatment.
Chouliara et al. 2004b.	Care settings. Specialist and non-specialist provision. Patient experience.	Scotland	Older cancer patient experiences in hospital. Mixed diagnosis.	6	Qualitative Semi-structured interviews.	Differences in care within the two settings. Inappropriate care and choices. Lack of choice and information in older person ward.
Thomé and Hallberg 2004.	Patient experiences; quality of life older person.	Sweden	Quality of life in older people with cancer – gender perspective	150	EORTC, SF-12 and SOC-13.	Gender, comorbidities, poor resources may burden cancer patients more than their illness. Women looked to their grandchildren than the male counterparts. Women more lonely. Women more comorbidities patients.
Duggleby et al. 2010.	Patient experiences; mixed diagnosis of lung, stomach and pancreatic cancer (all advanced cancer).	Canada	Patients with advanced cancer living in a rural setting.	Qualitative study using 27 interviews with different genders. Six older rural persons (over 60 years old) with mixed diagnosis of lung, stomach and pancreatic cancer (all advanced cancer).	Interviews	This study gave a deeper insight into older people living with advanced cancer, attending to the transitional processes which older people experience, such as their particular psychosocial adaptations and living with uncertainty, especially when living in rural environments.
Terrill and Gullifer 2010.	Patient experiences, life course issues. Gender/old age.	Australia Rural	Explore Older women's experiences of being older (out hospital).	8	Qualitative narratives.	Application of Erickson model in discussing the growth within older life and the process of adaptation. Being positive. Free and easy, growth and stagnation. Self-work.

Appendix C: Sampling grids

Sampling grid for semi-structured interviews of professionals on the specialist ward

	Past losses to cancer or chronic illness	Professional qualifications	Past experiences in care	Supportive care
Male (2)	None known.	Certificate in administration of chemotherapy (1). Diploma in Nursing (1). Older person qualification (0).	Cancer centre experience (1).	Spiritual support (1). All stages of cancer trajectory (1).
Female (3)	All had experienced past losses (2).	Cancer care level 11 module (1)[100]. Diploma in Nursing (3). Counselling course (1). Certificate in administration of chemotherapy (2). Older person qualification (0).	Medical (3).	All stages of cancer trajectory (3).

Sampling grid for semi-structured interviews of professionals on the medical ward

	Past losses to cancer or chronic illness	Professional qualifications	Past experiences in care	Care mostly experienced
Female (5)	All had experienced past losses (3).	Post-registration course on cancer (1). Post-registration course on palliative care (2). Diploma in Nursing (5). Older person qualification (0).	Medical (5).	Supportive or palliative care stages of cancer trajectory (5).

[100] Level 11 denotes a masters-level course.

Sampling grid for semi-structured interviews of patients on the medical ward

	Past losses to cancer or chronic illness	Age	Stage/palliative supportive	Family support	Previous cancer/chronic illness
Male (3)	Friend (1).	Above 75 (2).	Unknown primary (1). Palliative (2) (prostate and lung). Supportive (1) (prostate). Colorectal (1).	Married (2). Divorced (1).	Cardiac disease (2).
Female (2).	Mother/ Father (1). Husband (1).	Above 75 (3).	Lung (2). Palliative care (2).	Daughter (1). Grandchildren (2). Son (1).	Arthritis (1). Cardiac disease (2).

Sampling grid for semi-structured interviews of patients on the specialist ward

	Past losses to cancer or chronic illness	Age	Disease stage/palliative supportive	Family support	Previous cancer/chronic illness
Male (3).	Wife (2) (both to cancer).	Above 75 (3).	Liver (1). Active (1) (Haematology).	Married (3).	Cardiac disease (2). Previous cancer (1).
Female (2).	Friend (1).	Above 75 (2).	Breast with metastases (2).	Divorced (1). Daughter (1). Sister (1).	0.

Appendix D: Interview schedules

1. Pilot focus group: health care professionals

Tell me about your different professional backgrounds?

- Past experience
- Past roles
- Older person care
- Cancer care

Tell me about the older patients with cancer?

- Age
- Type of treatment
- Palliative care
- Active treatment
- Referral pattern
- Elective
- Routine

Give out stimulus material (1)

What are your thoughts on this scenario?

- Decision making
- Care delivery
- Social perceptions
- Gender related issues

Give out stimulus material (2)[101]

How do you see the older person with cancer?

- Older rather than cancer
- Cancer rather than older
- Both
- Palliative
- Active

[101] An example of stimulus material (2) is given in Appendix P.

What are the challenges of care delivery in this ward?

What are the promoters to care in this ward?

- Patients
- Specialty
- Resources

Is there any aspect of your role you find difficult?

- Emotional
- Clinical

What advice would you give a professional coming to this ward?

2. Agenda for Semi-Structured Interviews – Health Care Professionals

What does the older person with cancer mean to you?

- Social perceptions
- Complex needs

Can you tell me what experience you have had of cancer patients?

- Past work
- Past lives
- Experience
- Education

What factors have contributed to these views?

- Past lives
- Education
- Experience

What does the older patient with cancer mean to you in comparison to one that is below 65?

- Age
- Stage
- Treatment intent
- Social beliefs

How do these values affect your perspectives of care delivery?

- Age
- Stage
- Treatment intent
- Social beliefs

Can you tell me about the care you would give to an older patient who is older than 74?

- Supportive care
- Interventions

How do you assess care for the older person with cancer?

- Referral patterns
- Destination of care
- Interdisciplinary working

How does the ward shape your professional role and response to care delivery?

- Stage of disease
- Diagnosis
- Age
- Experience
- Education

Can you tell me about the care that older patients with cancer receive on this ward?

- Care interventions
- Types of illness
- Repeated admissions
- Acute admissions
- Psychosocial care
- Information
- Management of symptoms

What are the key aspects to your role in delivering care for older people with cancer*?*

- Physical care
- Psychosocial care
- Symptom management
- Supportive care
- Stage related

How do you respond to complex issues, such as older patients who are in the palliative care stages?

- Referral patterns
- Symptom management
- Interdisciplinary working
- Place of care

Can you tell me about positive aspects of the ward which help patients?

- Familiarity
- Knowing patients
- Interdisciplinary working

Can you tell me about the challenging aspects of the ward surrounding the care you give?

- Supportive care
- Symptom management
- Psychosocial care

What are the attributes in caring for the older patient with cancer?

- Emotional engagement
- Education knowledge
- Experience

Is there any aspect of the role you find difficult?

- Clinical
- Managing symptoms
- Communication
- Emotional

What is particular to your role?

- Clinical
- Emotional

Knowing what you know now, what advice would you give someone wanting to care for the older person with cancer?

- Experience
- Education

3. Agenda for Semi-Structured Interviews – Patients

Is this the first time you have been in hospital?

- Past experience
- Previous losses
- Previous experiences

Is this experience any different from past admissions?

- What is similar?
- What is different?

How do you manage at home?

- Existing illness
- Past illness
- Family support

How was your experience when you come into hospital?

- Different from home?
- What about the care here?
- How is it different from other experiences?
- Have you ever been in * ward

What makes it different or similar?

- Professionals
- Care experience
- Support of family

What does the ward provide for you?

- Symptom management
- Social support
- Emotional support

Can you give me an example of a physical and social aspect?

- Supportive care

Would you cope differently if you were younger?

- Past experiences
- Past losses

How are you coping with your illness?

- What helps your experience
- What do you do if you have less good days
- Do you have any symptoms
- How does this make it different than past illness

How do you interact with the professionals?

- Information
- Difficult questions
- Asking for help
- Supportive needs

Tell me about the care here?

- What is good
- What is not so good

If you had any advice for any other patients like you coming into hospital what advice would you give them?

4. Questioning route for Dissemination Focus Groups

Presentation of research

Give out stimulus material

Questions:

Do you think it is helpful to think of the ward as a halfway house?

- Clinical space
- Physical space
- Safe space
- Emotional space

Some examples?

Is etiquette helpful or is it in fact a barrier?

- Emotional norms
- Moral issues
- Informational giving

Some examples?

Do you recognize any of these patterns of emotion work, how patients manage feelings?

- Superficial
- Being authentic
- Reflective
- Therapeutic relationship

Some examples?

How do you think about the use of hope?

- Symptoms
- Treatment
- Wants
- Expectations

Some examples

Appendix E: Questioning routes

Development of questioning routes

A detailed questioning route was used to guide the discussion in both focus groups and semi-structured interviews. The aim of questioning routes is to encourage discussions on topics of interest while remaining flexible to data generation. It is also important to ensure that questioning follows a logical sequence of simply stated questions (Kvale, 2007). The planning of the questioning routes took time, comparing the themes of the literature review with the research questions. However, putting too much attention on getting the right questions in the right order can result in a peculiar social dynamic which can be unsatisfactory (Mason, 2002).

When considering the questioning routes, the aim is to generate meaningful knowledge (Mason, 2002). Importance is placed on ensuring there is a construction of knowledge and that the interviews are focused.

Using the main themes from the literature review, focus groups and piloting of questioning prompts helped to generate questioning routes. For example, in the professional semi-structured topic guide one of the research questions was:

- How do the two wards shape professional roles and responses to care delivery?

This research question was further broken down into:

- What are the key aspects to your role in delivering care for older people with cancer?
- How do you respond to complex issues, such as older patients who are in the palliative care stages?

From the smaller questions, specific prompts were created. Prompts enable the researcher to ensure that questions are being covered. They serve as an ‘aide memoire’ for the researcher to raise any issues that have not previously been mentioned. However, it is important not to be too prescriptive with prompts, in order to lead people to talk about issues on their own.

An example of one of the prompts is:

- How does the ward shape your professional role and response to care delivery?
    - Stage of disease
    - Diagnosis
    - Age
    - Experience
    - Education

Topics were not linear, but were rather flexible as to responses. The questioning was developed to be as non-threatening as possible. The sequence of all of the interviews was essential, beginning with open-ended, non-threatening questions and building up to ones that were more sensitive.

Focus group questioning prompts

In the initial focus groups, the use of a strategically placed 'vignette'[102] was used to stimulate discussion and also to afford comparison across groups. The vignette was a hypothetical typical clinical issue for the older person with cancer. The vignette was helpful in creating group discussion. It also helped respondents to compare and contrast their own experiences.

Both sets of focus group data gave insight into how the focus groups interacted within a ward team. Thus, there was a collective identity that informed the group 'focus of care'. The development of thematic grids[103] enabled the initial coding which generated further insight into the data. Analysis from the focus groups also aided in the development of questioning routes for the semi-structured interviews with professionals and patients.

Patient questioning routes

Designing the questioning route for patients was related to the main research questions. An example of the main research question was:

- How do the two wards shape the psychosocial experiences of older patients?

The question was further broken down into smaller questions:

  - What does the ward provide for you?

[102] A case vignette is defined as stimulus material which encourages and helps focus discussion around the topics the research is likely to address.

[103] Thematic grids relate to main issues arising from the data in terms of the frequency with which they occur.

- Can you give me an example of a physical and social aspect?
- Would you cope differently if you were younger?

This example of prompts explored the personal account and the context of where the patients' understanding of the disease comes from. After each interview with both patients and professionals, more topics could be added in order to focus more on emergent themes.

Questioning routes – dissemination focus groups

As discussed earlier for the dissemination focus groups, quotes from the focus groups and interviews were used as 'stimulus material'. The different coloured headings and quotations identified in analysis were: The Ward as Halfway House, Etiquette, Emotion Work and Hope. Specific questions related to how familiar the data were to professionals, in what ways and why. There were also prompts which were used to further envelop categories.

An example of a main research question relating to one of the major codes was:

- Do you think it is helpful to think of the ward 'as a halfway house?'

The question was further broken down into smaller prompts:

- Focus of care
- Emotional space
- Physical space

The benefit was in letting the professionals look at the quotations (I also gave them a handout) and to discuss as a group. This generated the various views while the stimulus material enabled added potential in furnishing explanations for patient and professional accounts. This also allowed me to review the difference in responses of participants to tentative findings. Barbour (2008) states that dissemination focus groups acknowledge that the researcher is not the expert and so enable researchers to acknowledge any puzzling patterns and to ask further questions.

Appendix F: Particular skills during focus groups and dissemination focus groups

My aim was to be as flexible and responsive to participants as possible and to note the context in which the focus groups occurred. Some respondents knew me from being previously interviewed or when I previously spoke with them when visiting the wards. The location worked to generate familiarity both for me and for professionals in their usual workplace. Establishing rapport was a way to gain deeper insights into participants' understandings of their reality.

Krueger and Casey (2000) state, however, that the researcher should note any hierarchies within a group, as this may hinder disclosure due to the power imbalance within the group. However, since these can be alleviated in a semi-structured interview context, this was an advantage of combining the two methods of data collection.

I also kept notes on what was being said – or, indeed, not being said – together with notes on non-verbal behaviour, which can be more powerful and meaningful than verbalized comments (Burnard, 1992). However, it should be noted that the interpersonal dynamics of the group can alter the way data is gained. Thus, the data is formed from what the group feels together and is therefore a 'co-construction of meaning' (Wilkinson, 1998). To acknowledge the dynamics, it is important to note the way participants answer questions or acknowledge experiences of others. The focus group was also therapeutic in enabling members to talk, meaning they might thereafter view experiences differently. Data

collection can also be seen as enhancing aspects of patients' care (Entwistle et al., 2002). However, the researcher noted if subjects seemed to feel threatened.

Particular skills during interviews

Sensitive questioning skills such as listening, attending, reflecting and summarising were essential in generating the data. Repeating key themes and messages of the participant's responses was also important to ensure I understood meanings of their accounts and attended to both non-verbal and verbal cues. Some respondents asked if what they were saying and how they were telling their stories was correct, in order to counteract their feelings that talking was wrong. I was always attentive in praising them for their accounts and reassuring them that the way they phrased their accounts was exactly what was wanted. Encouraging participants to use their own words and tell their own story was extremely pertinent to the authenticity and representation of the data. While how the researcher carries out data collection is essential, the importance of field notes is seminal to allow the reflective and interpretative role of the researcher.

Appendix G: Charting grids

An example of a grid from the specialist and medical ward is given below demonstrating the process of 'counting' during a Focus Group (FG) (Silverman, 1993).

Challenges	Philosophy of care	Education and experience	Delivering palliative care	Psychosocial care
Focus Group specialist (3 senior nurses)	√√ (Not getting too close)	√ (Emotion work)	√√ (Stopping treatment)	√√ (Knowing patients over time)
Focus Group medical (3 senior nurses)	√ (Past losses)	√√√ (Lack of training, fewer specialists)	√√√ (Referral to palliative care team) √√ (Symptom management)	√√ (Not knowing what to say and not getting too close)

An example of the process of 'charting' within the thematic grids relating to the major theme of hope.

Patient accounts relating to hope: medical and specialist ward.

	Particularized hope	Generalized hope	Clinical	Social	Past lives
Interview 1, Medical ward	Hope I don't die like him.				
Interview 2, Medical ward		I hope there is a God.		I just want to go home and pick the tatties.	
Interview 3, Medical ward			I just want the pain to go away, then I can listen.		My dad died of a heart attack – I would rather go like him.
Interview 4, Medical ward				I hope I get home to go on holiday.	

Interview 5, Specialist ward			I do not want chemo therapy any more. I just want to go – I can no longer go on like this.		

Professional accounts from specialist and medical wards.

	Particularized hope	Generalized hope	Clinical	Social	Past lives
Interview 1, Specialist ward		The treatment here is massive.			
Interview 2, Medical ward	We try and offer more than getting their pain sorted here.		You don't want to say, as it may not be true.		I had a son who died.
Interview 3, Specialist ward			I miss them and hope they are well.		
Interview 4, Medical ward					I am a cancer survivor myself.
Interview 5, Specialist ward				I do not want to lose the hope they have.	

Appendix H: The care environment

Themes, categories and codes.

Themes	Categories	Codes
• Uncoordinated care process. • Oncologist not available on site. • Had to travel for radiotherapy. • Wards have different focus of care. • Referral system to specialist nurses unclear. • Patients knew of the organizational pressure but tended to wait in their place in the queue.	Fragmented system. Specialist nurse referral not consistent.	The challenges of a cancer unit.
• Individual rooms encouraged the opportunity to unite both clinical and psychosocial interventions. • Specialist ward was a more tranquil environment. • The benefit of being with fellow patients within the four bedded bay, highlights the importance of mutual support. • Comparison to others enabled a social identity.	Four bedded bay versus single rooms. Company versus privacy.	Ward layout and characteristics.
• Specialist more haematology related. • Medical ward more respiratory related. • Specialist ward more	Notion of sameness versus different specialties. Clinical versus social.	Focus of care.

interventionist. • Medical ward more palliative. • On both wards they oscillated between the clinical side and the social side • Both wards were not cancer and older person focused. • Staff in the specialist ward enjoyed care which was one specialty. Being cancer focused thus encouraged a notion of sameness.		
• Patients felt safe in the ward, while living with uncertainty and adapting to transitions in their illness. • The medical ward could be seen as a 'holding bay' while further tests were being carried out or until the next place. • The fact that in the specialist ward patients could self-admit promotes this sense of safety. • The issue of safety was clear amongst patients' accounts, feeling reassured by the comfort of professionals' clinical expertise. • It appeared that being clinically safe was also related to being psychologically safe which is reflected in the words of 'they	Transitions, safety, being a patient. Clinical and emotional safety. Destination of care. Therapeutic culture.	Ward as a 'halfway house'.

care about me'. • Ward as safe also recognized the fact that patients knew the staff from previous admissions. • 'Being a patient' legitimating the relinquishing of her other roles. • Hospitalization served as a place where patients had the opportunity to express fears and worries. • Being in hospital gave the family a rest from caring. • Nurses knew more about patients social and clinical needs.	Being a patient: change of roles.	
• Patients perceived trust in different ways depending on different perceptions. • 'God-like'. • Active participation in care. • Misunderstanding. • Not hearing. • Professional power evident.	Absolute trust. Active participation. Misunderstanding.	Trust.
• Looking to the social as well as the physical on specialist ward. • Medical ward more physically orientated. • Staff on the medical ward being rushed of their feet did not help familiarity. • Taking time with patients helped familiarity. • Side rooms gave privacy for	Getting to know patients; ward design. Side rooms versus four bedded bays. Familiarity through knowing patient and ward design.	Familiarity.

professionals to talk. • Side rooms prevented interaction with other patients in specialist ward. • Some patients knew the ward they were in due to their nurse role or caring for their wife.		
• The stages of the cancer journey define different aspects of treatment which relate to diagnostic, treatment or palliative stages. • Symptoms with comorbidities added to complexity of need.	Stage of illness and multimorbidity. Supportive care versus focus of care.	Stages in cancer journey.
• The medical ward had an emphasis on teaching in relation to respiratory care, whereas the specialist ward had an interest in developing skills in haematological care. • Neither ward had specific educational outcome to be qualified in gerontology, geriatric medicine or cancer. • Staff felt that education in cancer lessened the 'scary word' cancer.	Social and emotional aspects of education.	Education, cancer, gerontology.
• Working with other clinical nurse specialists facilitated decision-making, but the process of when to involve others was often unclear, as there	Referral guidelines. Focus of care. Cessation of treatment.	Referral to specialists.

was no written protocol for referral. • The tension in stopping treatment and thus moving to palliative care made the referral pattern to the palliative care team a challenge.		
• The clinical experience of physical disruption of patients related to pain, breathlessness and side effects of chemotherapy treatment often disrupted patients' previous assumptions relating to their quality of life.	Process of giving physical care was valuable in assessing patients' needs.	Experiencing symptoms.
• Transition to palliative care. • Role of specialist nurse. • Role of nurses. • Giving up and loosing fight (professional). • Dealing with symptoms-specialty. • Dealing with symptoms, multimorbidity, polypharmacy. • Process of symptom management. • Rationalising treatment. • Advocacy for patient. • Power conflicts. • Informed consent. • Tension between specialist and generalist nursing. • Independence and dependence.	Challenges in decision making. Cessation of treatment. Self-management versus dependence.	The transition to palliative care.

Appendix I: Ethics approval document

NHS Fife NHS Forth Valley NHS Tayside

Fife, Forth Valley & Tayside Research Ethics Service

Fife & Forth Valley Committee on Medical Research Ethics
Research Ethics Office
Level 9
Ninewells Hospital & Medical School
DUNDEE
DD1 9SY

Ms A Lannie
Lecturer
University of Dundee
Forth Avenue
Kirkcaldy
KY2 5YS

Date: 10 June 2008
Your Ref:
Our Ref: FB/LR/**08/S0501/33**
Enquiries to: Miss Fiona Bain
Extension: Ninewells extension 35598
Direct Line: 01382 425598
Email: fionabain@nhs.net

Dear Ms Lannie

Full title of study: **An exploration of patients and health care professionals perspectives of the older persons' cancer care delivery within a general hospital using a multiple case study approach**

REC reference number: **08/S0501/33**

Thank you for your letter of , responding to the Committee's request for further information on the above research and submitting revised documentation, subject to the conditions specified below.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

POSITIVE ABOUT DISABLED PEOPLE

Document	Version	Date
Application		10 April 2008
Investigator CV		09 April 2008
Protocol	1	07 April 2008
Covering Letter		10 April 2008
Letter from Sponsor		10 April 2008
Compensation Arrangements		05 September 2007
Compensation Arrangements		07 November 2007
Interview Schedules/Topic Guides	Agenda for Semi Structured Interviews - Health Care Professionals	07 April 2008
Interview Schedules/Topic Guides	Focus Groups Themes	07 April 2008
Interview Schedules/Topic Guides	Agenda for Semi Structured Interviews - Patients	07 April 2008
GP/Consultant Information Sheets	2	
Participant Information Sheet: Consultant Information Sheet	2	
Participant Information Sheet: Patient Information She	2	
Participant Information Sheet: Staff Information Sheet	2	
Participant Consent Form: Patient Consent Form	2	
Participant Consent Form: Staff Consent Form	2	
Response to Request for Further Information		
Letter of Support, Caroline Arnott, Clincial Nurse Man		26 May 2008
Declaration of educational supervisor	Jo Corlett	19 May 2008
Approval from Clinical Nurse Manager	Caroline Arnott	26 May 2008
Confirmation of ability to provide appropriate support		23 May 2008
Confirmation of PHD Candidacy, Mr M Glover		28 March 2008
CV, Dr J Corlett		08 April 2008
CV, Professor W Lauder		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/S0501/33	**Please quote this number on all correspondence**

Yours sincerely

L. Kelly

for **Mr Gavin Costa**
Chair

Enclosures: "After ethical review – guidance for researchers"
Site approval form

Copy to: Mr James Houston, Research & Innovation Services, University of Dundee
NHS Fife R&D office

Fife and Forth Valley REC

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	**08/S0501/33**	**Issue number:**	1	**Date of issue:**	10 June 2008
Chief Investigator:	Ms A Lannie				
Full title of study:	An exploration of patients and health care professionals perspectives of the older persons' cancer care delivery within a general hospital using a multiple case study approach				

This study was given a favourable ethical opinion by Fife and Forth Valley REC on 10 June 2008. *The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.*

Principal Investigator	Post	Research site	Site assessor	Date of favourable opinion for this site	Notes (1)
Ms A Lannie	Lecturer	NHS Fife	Fife and Forth Valley REC	10/06/2008	

Approved by the Chair on behalf of the REC:

L. Reilly ..... (Signature of ~~Chair~~/Assistant Administration Manager)

(delete as applicable)

MRS LORRAINE REILLY ..... (Name)

(1) *The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.*

Appendix J: Patient information sheet

Patient information sheet
"Exploring the care received by older cancer patients in a general hospital"

This is an invitation to take part in a research study that is being conducted in part fulfilment of a PhD degree award at the University of Dundee. The Fife & Forth Valley Research Ethics Committee, which has responsibility for scrutinising proposals for medical research on humans, has examined this proposal and has raised no objections from the point of view of medical ethics.
Before you decide to participate I need to be sure you fully understand why I am doing it and what it would involve if you agreed to take part. Please read the following carefully and take time before deciding whether to take part. If you have any questions I will do my best to answer them.

Background to the study
The aim of the study is to explore the experience of patients while being in this particular ward. I want to know your experiences of living with your illness, its treatment, the care you have received in this ward and how it helps you to cope. I am interested in good experiences as well as bad ones, and particularly in any aspects of your care which could be improved.

Why have I been chosen ?
You have been chosen because you are currently a patient on this ward.

Do I have to take part?
No, it is up to you whether you decide to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign the consent form overleaf.

Can I change my mind about the project?

Yes. If you decide to take part you may change your mind at any time and without giving a reason, without this affecting your present or future medical care or your relationship with your doctors and nurses.

What will happen to me if I take part?
You will be asked to have an interview with me at a time that's convenient to you which I will arrange. Before the interview you will be given the opportunity to discuss the study again and I will ask you to sign a consent form. The interview can be done either in the ward, in a side room, or in a suitable place that you would like. The interview is likely to last up to one or one and a half hours but if this is too long, or you get tired we can stop anytime you wish and continue it at a later time to suit you. If you prefer you may bring a friend or relative to the interview. I will tape record the interview, but only with your permission. This is to allow me to have a record of our conversation and to avoid me having to take notes at the time. However, if you do not wish to have it recorded we can still do the interview.

What are the possible benefits of the study?

The study will help the ward staff understand more about the care received during your stay. By helping us to understand your experiences it is hoped that the results will inform future care delivery

Will my taking part in the study be kept confidential?
Yes. Your name will not be known to anyone other than me and no information you provide will be given to anyone outside the research team. All comments you make are confidential and will not be given to the ward staff. Later, when all the interviews are completed only a summary of the comments made by patients will be given to the ward staff. The audio recordings will be destroyed after transcription has taken place. I am likely to report individual quotations 'only where I am satisfied that it will not be possible to identify the person making such statements. The interview transcripts will be securely stored at the University of Dundee and held for a period of 5 years after the study ends.

What will happen with the results?
The results from the study will be complete by 2011. However before then results will be acted upon prior to your research being written up in a formal

report I will discuss my findings with staff on the ward and other lead health professionals. I will also publish my findings in medical journals but you will not be identifiable in any of the reports.

What happens now?
If you agree your nurse or Doctor will pass on your name and ward to me. That day or the following day, I will come and see you to answer any questions you may have. If you are still interested you will sign a consent form we will arrange a suitable time for the interview.
Thank you for taking the time to read this information sheet. If you require any further information please contact me on 07809443026
Thank you for reading this Information Sheet and considering taking part in this study
Antonia Lannie,
Researcher

Consent form

Ward:
Patient Identification Number:

Title of Project: "Exploring the care received by older cancer patients in a general hospital"

Name of Researcher: Antonia Lannie

Please initial box

1. I confirm that I have read and understood the information sheet dated Version 2 08/S0501/33 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any medical care or legal rights being affected ☐
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Dundee, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I agree to my consultant being informed of my participation in the study. ☐
5. I consent for audio recordings of the interviews ☐
6. I consent for reporting direct quotations arising out of the interviews ☐
7. I agree to take part in the above study ☐

_____ _____

Name of participant Date
Signature

_____ _____

Name of person taking consent Date
Signature

When complete, 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes

Staff Information Sheet.

"Exploring the care received by older cancer patients in a general hospital"

This is an invitation to take part in a research study that is being conducted in part fulfilment of a PhD degree award at the University of Dundee. The Fife & Forth Valley Research Ethics Committee, which has responsibility for scrutinising proposals for medical research on humans, has examined this proposal and has raised no objections from the point of view of medical ethics.
Before you decide to participate I need to be sure you fully understand why I am doing it and what it would involve if you agreed to take part. Please read the following carefully and if you want to discuss any questions I will do my best to explain and provide any further information.

Background to the study
I am a nurse and a Lecturer / post graduate student working on my Ph. D at Dundee University within the department of Nursing and Midwifery. The aim of the study is to explore patients' and health care professionals' perspective of older cancer care delivery within a general hospital, in particular the ward you practice in.

Why have I been chosen?
I want to understand more about the care that is provided for the older patient with cancer. You have been selected because you work on the ward and are involved with patients who have cancer.

Do I have to take part?
No, it is up to you whether you decide to take part. If you do decide to participate, you will be given this information sheet to keep and asked to sign a consent form overleaf.

Can I change my mind about the project?

Yes. If you decide to take part you may change your mind at any time and without giving a reason.

What will happen to me if I take part?
You would be invited to participate in a semi structured interview or focus group or both. The interview and focus group will be recorded to avoid me having to take notes at the time. However, if for an interview you do not wish to have the conversation recorded this can be arranged.
If you would like to take part in the interviews I will contact you to arrange a convenient time for this to take place. You will be given the opportunity to discuss the study again and I will ask you to give written consent prior to the interview.
For a focus group I would like to assemble groups of six to eight health care professionals who work with you on the ward. These interviews would take place in locations that are convenient for the majority of participants such as meeting rooms or on the ward. Each focus group interview is likely to last approximately up to 1- 1.5 hours. You may prefer to be interviewed on a one-to-one basis rather than in a group and I am happy to respect your wishes. One-to-one interviews can be undertaken in a place convenient to yourself- on or off the ward. These are also likely to last between 1-1.5 hours, with the nurse manager's agreement.

What will happen to the information collected in the study?
All data gathered will be anonymised and entered into a computer database. The results of this project will be disseminated at various conferences and meetings but your identity will remain anonymous. All recordings will be destroyed when data analysis is complete. None of the nursing or medical staff will have access to interview transcripts. If malpractice came to light in the course of the study, I am obliged to inform the charge nurse.
What are the possible benefits of the study?
The study will help health care professionals understand more about cancer care delivery in a general hospital. By helping me to understand your experiences we hope that patients who are diagnosed with cancer will get the best possible care.

Will my taking part in the study be kept confidential?
Yes. Your name will not be known within the data generated, to anyone other than myself and no information will be given to anyone. The audio recordings will be destroyed after transcription has taken place. I am likely to report

individual quotations 'only where I am satisfied that it will not be possible to identify the person making such statements. The interview transcripts will be securely stored at the University of Dundee and held for a period of 5 years after the study ends.

What will happen with the results?

The results from the study will be complete by 2011. However before then results will be acted upon prior to your research being written up in a formal report. I will discuss my findings with staff on the ward and other lead health professionals. I will also publish my findings in medical journals but you will not be identifiable in any of the reports.

Thank you for taking the time to read this information sheet. If you require any further information please contact me on 01592 268888 or a.lannie@dundee.ac.uk
Thank you for reading this Information Sheet and considering taking part in this study
Antonia Lannie
Researcher

Consent form

Staff name:

"Exploring the care received by older cancer patients in a general hospital"

Ward name

CONSENT FORM FOR STAFF FOCUS GROUP

Title of Project: "Exploring the care received by older cancer patients in a general hospital"

Please initial box

7. I confirm that I have read and understood the information sheet dated Version 2 08/S0501/33 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
8. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected ☐
9. I consent for audio recordings of the focus groups. ☐
10. I consent for reporting direct quotations arising out of the interviews ☐
11. I agree to take part in the above study. ☐

Name of participant Date Signature

Name of person taking consent Date Signature
When complete, 1 for participant; 1 for researcher site file;

Consent form

Staff name:

Ward base;

CONSENT FORM FOR STAFF INTERVIEW

Title of Project: "Exploring the care received by older cancer patients in a general hospital"

Name of Researcher: Antonia Lannie Please initial box

1 I confirm that I have read and understood the information sheet dated Version 2 08/S0501/33 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2 I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected ☐

3 I consent for audio recordings of the interviews ☐

4 I consent for reporting direct quotations arising out of the interviews ☐

5 I agree to take part in the above study. ☐

Name of participant Date Signature

Name of person taking consent Date Signature

When complete, 1 for participant; 1 for researcher site file;

Consultant sheet

This is an information sheet regarding a research study that is being conducted in part fulfilment of a PhD degree award at the University of Dundee. The Fife & Forth Valley Research Ethics Committee, which has responsibility for scrutinising proposals for medical research on humans, has examined this proposal and has raised no objections from the point of view of medical ethics.
The title of the study is; to explore the patients' and health care professionals' perspective of older cancer care delivery within a general hospital.

Before patients consent, they need to be sure firstly why I am doing it and secondly what it would involve if they agreed. I am therefore providing you with the following information. If you want to discuss any questions I will do my best to explain and provide any further information about the study.

Background to the study

I am a nurse and a Lecturer / post graduate student working on my Ph. D at Dundee University within the department of Nursing and midwifery. The aim of the study is to explore the patients' and health care professionals' perspective of older cancer care delivery within a general hospital, in particular the ward you practice in.

What does the study entail?

Patients would be invited to participate in a semi structured interview. If they would like to take part in the interviews I will contact them to arrange a convenient time for these to take place. The patient will be given the opportunity to discuss the study again and will be asked for written consent

prior to the interview. One-to-one interviews can be undertaken in a place convenient to the patient- on the ward. This is likely to last up to an hour or less.

What will happen to the information collected in the study?
All data gathered will be anonymised and entered into a computer base. All interviews will be recorded on minidisk. All names will be coded and the discs stored in a locked cabinet. Files stored on computer are password protected. The only other people who will have access transcripts will be my Ph.D supervisors who will be unaware of identity. The results of this project will be disseminated at various conferences and meetings but identity will remain anonymous. None of the nursing or medical staff will have access to interviews. The audio recordings will be destroyed after transcription has taken place. I am likely to report individual quotations 'only where I am satisfied that it will not be possible to identify the person making such statements. The interview transcripts will be securely stored at the University of Dundee and held for a period of 5 years after the study ends.

Participation in this study is entirely voluntary and patients are free to refuse to take part or withdraw from the study at any time without having to give a reason.

Thank you for reading this Information Sheet and considering taking part in this study . If you require any further information please contact me on
01592 268888
Antonia Lannie
Lecturer/Postgraduate Student

Appendix K: Emotional adaptations of the older person in two ward settings

	Look to their past lives in occupations	**Past family members**	**Dealing with other people**	**Relating to their gender**	**Reflecting on their age**	**Comparing to others**	**Looking to professionals**
Mary	I was a teacher so understand their (professionals) control.		You have to ask them … they don't like it, though.	I like being a granny more, woman-to-woman.		Remember Jane Tomlinson; she was strong.	They make me feel wanted, I am not just a number here.
David	They are more professional than my colleagues in the catering.	My first wife died of cancer and my present partner had Hodgkin's disease.		I was always the head of the family and have headed up many restaurants - I was the boss.		I look to the younger ones and like to ask if they are OK.	These staff are like angels.
Janet		I remember when my neighbour was ill. He had cancer and he died quick. I don't want to die.		I like to protect my grandchildren from all this. I don't want them to know I have cancer.		My cousin had breast cancer also.	I think she may have had an argument with her husband last night.
Bertie		I don't want to die this way. I have had enough.		I was just the dad; they were more with their mum all their lives … so they left me, darling	I don't care, darling; they should just shoot me.	I am fine with all my pals here.	The nurses are all lovely.

Ruth		I hope I go like my husband and have a heart attack rather than this.		I cared for the wains all my life, I was alone.		I felt sad for her she was worse off than me. I thought at least I have had a life. She is just young.	
Graham	I went through to Glasgow and joined the police and that's it. It's how we were brought up-old fashioned.				I have had a good life I wouldn't care if I died tomorrow.		They speak with mumbo jumbo.
Andrew	It's showing respect like I did as a painter.						Professionals are to be respected.
Alexander			If the parents showed some respect to their next door neighbour …. That's how I would look at it. I'm maybe old.				

Jinty	When I was a nurse, I would not have done that.	I don't get on with my family … my sister I don't like her. She complains of back pain, and I've got cancer … she never listens to me.		I had my breast off and have two wigs; what do I look like now … hardly top dog … she does not help….		I would have never been like that when I was the same as her….	She has funny vibes she does … she says don't worry but I do worry….
Colin		My wife had cancer I am not finished with leukaemia and now I have got this.			You think I am worried, I'm not worried…. I'm 78, you see, and if I died tomorrow it wouldn't worry me, it wouldn't worry me in the least.		It's talking to the staff, respecting the staff and listening to the staff. They know things we just don't know.

Appendix L: Patients' symptoms and other illnesses

Blue= Specialist Red= Medical Ward	Age	Diagnosis	Breathlessness	Fatigue	Weight Loss	Bone Pain	Head Pain	Pain on Moving	Treatment Side Effects	Other Illnesses/ multimorbidity
Mary	82	Breast with metastases		√		√			√ tinnitus	
David	78	Hairy cell leukaemia			√					√ cardiac disease
Colin	78	Prostate cancer				√		√		√ previous leukaemia
Graham	72	Liver metastases				√		√		√ cardiac disease
Jinty	72	Breast with metastases		√				√		
Janet	78	Lung cancer with metastases	√	√	√			√		√ arthritis
Bertie	82	Liver metastases, unknown primary	√	√			√	√		√ deafness
Ruth	78	Lung cancer with metastases	√	√	√			√		√ cardiac disease
Andrew	80	Colorectal cancer			√	√		√		√ cardiac disease
Alexander	75	Prostate cancer with bone metastases		√	√			√		√ deafness √ cardiac disease √ arthritis

Appendix M: Cancer discharges

Cancer discharges in Fife NHS Board
Over-65 Years of Age
April 2006 to March 2007

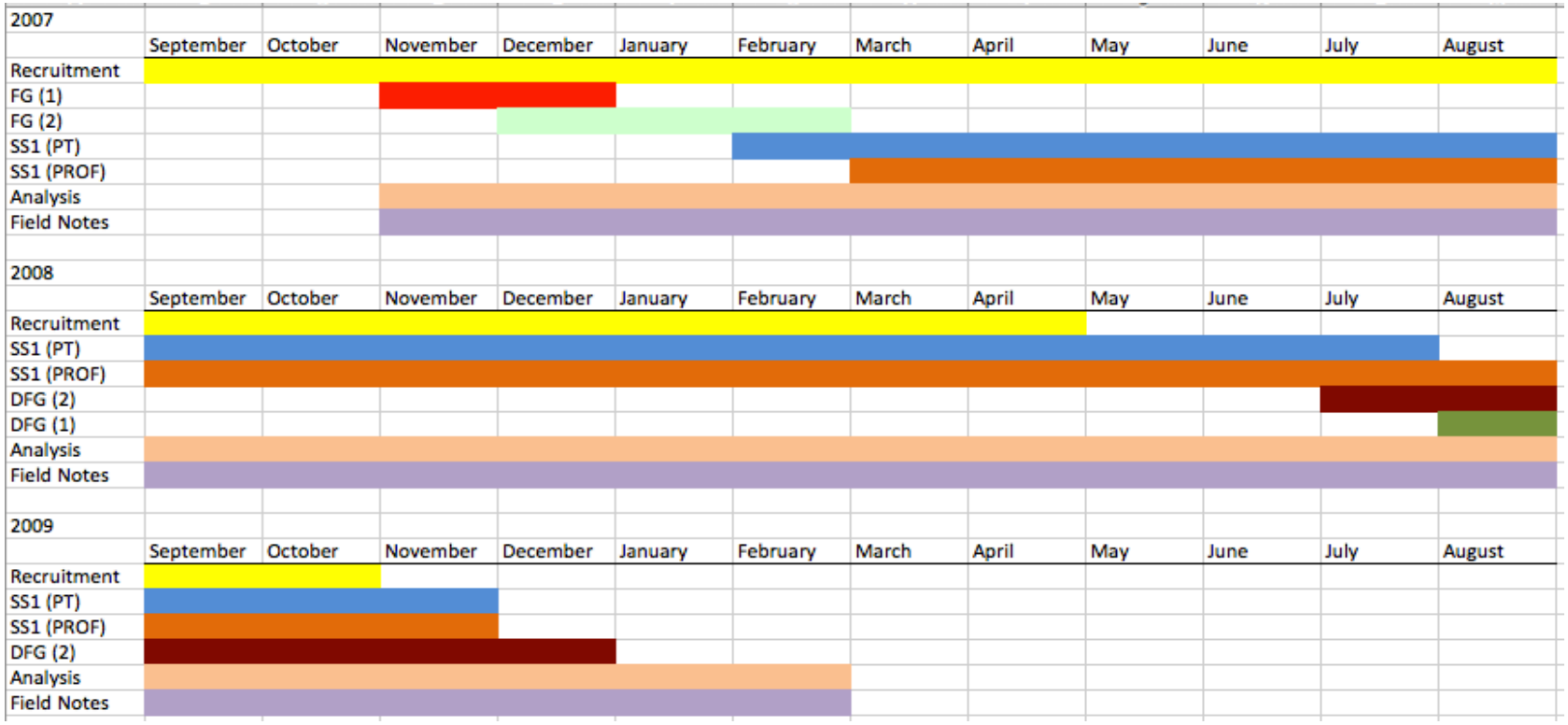
		Ward B			Ward B (Day bed area)			Ward A		
	Cancer Site	DC	IP	Total	DC	IP	Total	DC	IP	Total
	Breast	12	31	43	-	*	*	-	*	*
	Digestive Organs	181	218	399	*	*	10	*	*	*
	Eye, Brain, CNS	-	*	*	-	*	*	-	-	-
	Female Genital Organs	*	*	22	-	-	-	-	*	*
	Lip, Oral Cavity & Pharynx	*	*	17	-	*	*	-	-	-
	Lymphoid, Haematopoietic and Related Tissue	763	117	880	-	-	-	*	*	78
	Male Genital Organs	*	23	27	-	*	*	-	-	-

	Mesothelial & Soft Tissue	*	20	21	-	14	14	-	-	-
	Other	*	85	87	-	*	*	-	*	*
	Other Respiratory & Intrathoracic Organs	*	22	24	-	-	-	-	-	-
	Skin	*	*	145	-	-	-	-	-	-
	Thyroid & Endocrine Glands	-	*	*	-	-	-	-	-	-
	Trachea, Bronchus & Lung	140	295	435	*	*	134	-	51	51
	Urinary Tract	*	*	18	-	-	-	-	-	-
	Total	**1260**	**873**	**2133**	**27**	**146**	**173**	**26**	**111**	**137**
	Treatment Total	**2429**	**2239**	**4668**						

- Zero Value
* Suppressed due to risk of disclosure

Source: SMR01, Fife Information Services, Log Number: 2261

Appendix N: Timeline for recruitment



Appendix O: Field notes

Proximal care[104]

One particular aspect of care delivery: proximal care, was drawn to my attention. During an interview on the specialist ward (*place*) and reflecting on Staff Nurse Jones (*actor*) stating 'You just make the time … [more time to] sit down and ask what they really want' made me realise that to be engaged in emotion management, nurses had to be not only physically present with the patient but also to listen to their concerns. Giving time to patients to present their experiences may help them connect with their past experiences (*event*). Thinking about the value of the attributes of the ward settings enables my understanding. I appreciate the different ways older patients (*goals*) with cancer experience care in the context of the ward settings. This seems to help validate their experience and strengthen the therapeutic relationship.

Reflecting on Andrew's words (prostate cancer, medical ward) (*actor*) in an interview, 'Now I am getting the same help here but they are more professional than my wife is' made me think about the importance of giving physical care (*event*) for patients and that patients really see the importance of a professional doing this rather than a family member. A person-centred environment (*goal*) is key in facilitating older people with cancer the time to express the importance of receiving care from a professional rather than being at home. Both accounts enable me to understand the different ways physical care strengthens the patient experience and the professionals' sympathetic presence (field notes, April 2009).

Emotion work

Emotion work appears to be more than a professional aspect of caring. Reflecting on Staff Nurse Gamlin's account (*actor*) stating that 'they are all like family' makes me think that the notion of 'being a family' crosses over from the professional domain of being a nurse towards the person side of the professional. Considering that the attributes of a specialist ward (*place*) generates more of a therapeutic relationship this may also trigger a deeper emotional relationship with their patients. However, this also brings tensions as the person part of their self may conflict with their professional role. An example of this was when a nurse had said 'That could be my mum in that

[104] In Appendix O, the terms in brackets refer to categories within Spradley's (1980) framework.

bed' (*feelings*) which illustrates how nurses look to their personal experiences to influence their professional role in emotion management. In addition, these conflicting accounts were less in the medical ward, as professionals had not had such a therapeutic relationship with those patients. Another aspect of being closer to patients is the need to look after oneself professionally (*goal*). Giving time to reflect and discuss our professional experiences may help professionals understand the significance of giving a part of oneself to ensure authenticity (Specialist ward, August 2007).

Education

Looking at the data within the two wards reminds me that older people with cancer are heterogeneous rather than being perceived as all the same (*place*). An example of the complexities in helping patients make decisions (*event*) is when I heard a nurse in a focus group (*actor*) telling me that 'Where's the issue of the form of consent here?' when she discussed the older patient with dementia. This also makes me think that education is needed to inform professionals about gerontology and cancer (*goal*). In addition, understanding that dementia is also common and can affect choices for treatment.

However, it is perceived that education is a must in diverse wards but for different reasons. In the medical ward (*place*) professionals (*actors*) recognized that palliative care was important to all patients but not all were educated in palliative care. In the specialist ward, nurses recognized the need for palliative care but most had education in haematology diseases. Also, when considering the holistic management of clinical interventions for older people with cancer, education for professionals should also encompass aspects such as assessment of toxicities, comorbidities and polypharmacy so that appropriate care is given to older people with cancer (*goal*). Another important aspect is interdisciplinary working in and across both wards. Due to the different specialties of the ward settings (*place*) this results in different foci of care. This makes me question where the older person with cancer is better placed and that the attributes of that care setting would have to encompass education in cancer and gerontology but also to ensure interdisciplinary working of different teams (Specialist ward, December 2008).

Appendix P: Stimulus material for focus group

Mr Jones (78) was diagnosed with Ca lung. He also has cardiac disease. He is breathless and has right shoulder pain. He lives in a remote area of Glasgow. He is widowed and lives alone. His son lives nearby. He is attending the outpatient clinic to discuss chemotherapy. His doctor is suggesting that he does not have chemotherapy given his age and the fact he will have to travel. Mr Jones says he would rather do what the doctor suggests ‘as he knows best’. However, his son wants him to have chemotherapy.

Appendix Q: Attributes of person-centredness

Themes from study	**Theory and quotations**
The importance of emotional and physical safety. *For older people with cancer*: attention to physiological needs relating to the disease, cancer treatment and symptoms.	Patients felt that there was a caring which was safe physically and emotionally.
To feel safe within the context of care: receiving psychological care which attends to emotional needs during the transitions of their illness.	'They look after me, which my wife can't do at home.'
For staff: to have emotional needs recognized and to have systems in place to support caring for this particular group of patients, including an environment where professionals can reflect on the care they give within a supportive environment.	Professionals used different aspects of emotional engagement to ensure authenticity. However, constraints of time and a sense of not knowing what to say to patients hindered engagement at times.

The necessity for continuity of care. *For older people with cancer*: to recognize and value biography, the skilful use of knowledge of the past in contextualizing the present and future. To ensure patients are admitted to the same ward and patients establish a relationship with the same staff. To recognize the temporal nature of relationships and the ability to shape, renegotiate and align shared meaning. *For staff*: to have clear expectations and goals, as well as timely referral patterns to cancer, palliative and gerontology specialists.	'I'm used to it, having had cancer, and my wife died of cancer.' A sense of continuity was essential for participants to generate familiarity and trust. 'I like chatting to my pals; it dulls the pain.' Neither ward had any referral guidelines to cancer, geriatric or gerontology services.

The requisite for familiarity. *For older people with cancer*: to feel emotionally safe and maintain relationships with staff and fellow patients within the ward setting.	'It is like a family here.'
For staff: to feel valued as part of the team and to contribute to oncology and gerontology care.	Both wards needed collaborative working to ensure joint decision making.
A need to feel involved. *For older people with cancer:* to be able to look to expectations, goals and challenges, and to feel in control of choices.	Patients felt empowered when involved in decisions.
For staff: to work with patients to have a therapeutic direction and clear goals within cancer and gerontology to aspire to.	'I had to act as the patient's advocate to stop the treatment.'

To meet patients' expectations. *For older people with cancer*: to meet meaningful goals in relation to wants and expectations.	'Wanting to go home to watch the tatties grow.'
For staff: to be able to provide good therapeutic care, to work towards goals, and to use skills and ability to the full.	'To give [the] good part of you is key to good care.'
To nurture personhood. *For older people with cancer*: to feel recognized as a person and that one's actions and existence are of importance and that you 'matter'.	'It's good not just to feel you are a patient, but granny-to-granny.'
For staff: to feel that gerontology and cancer care are valued as important and interdependent.	The focus of care was different on each of the wards. There was little collaboration between cancer and gerontology care.